

# ANNEX VIII: NORWAY

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## 1. INTRODUCTION

This report gives an overview of the system of services for people with intellectual disabilities in Norway. The report is a part of the POMONA II project; “Health Indicators for People with Intellectual Disabilities”.<sup>1</sup> The report presents the service system in two chapters, one on social and one on health services. However, before the presentation, we will briefly address some background issues, such as the definition of intellectual disability, prevalence, the historical development of the service system, and the legal rights of citizens with intellectual disabilities.

It is also worth noting at the onset, that the service system in Norway is mainly public. Private providers play a minor and supplementary role. Local authorities are the key service provider, whereas the national government is providing hospital services and the cash benefit schemes. Furthermore, it is current ideology that services for people with intellectual disabilities (and also everyone else) should be integrated in the generic service system rather than being a specialised service for a specific group (White Paper No. 40, 2002–2003).

The definition of intellectual disability

If asking a medical doctor about the definition of intellectual disabilities in Norway, she will most likely refer to ICD-10 (WHO, 1992). But in practical reality, the issue is much more complex, with different types of definitions interacting. There are at least three types of definitions coexisting:

(1) All current policy documents and governmental reports tend to define disability, and accordingly intellectual disability, in relative and relational terms. The definition focuses on the interaction between the individual and his or hers environments. Disability is seen as a gap or disparity between the individual’s physical, psychological or intellectual functioning and the characteristics of the environment (for instance Public Committee Report No. 22, 2001). The definition is based on a socio-ecological perspective, not very dissimilar from the so-called biopsychosocial model underpinning the ICF (WHO, 2001). This understanding and definition do inform political initiatives, but plays virtually no role in any classification of people. Thus, in classification of people, two other definitions prevail.

(2) In parts of the service system, and particularly among the medical professions, the definition of intellectually disability is according to the ICD-10. The ICD has been the official diagnoses manual in Norway for years. However, in practice the trend is that the diagnosis of intellectual disability is replaced by more specific syndromes/diagnoses, and thus seems to be in less frequent use – for instance among paediatricians.

(3) The third definition is the “administrative” one. This is based on the individual’s need for support and services, for instance accommodation services. In practice, the definition of people with intellectual disability is thus “service users”. Before a person becomes a service user, there tend to be some kind of assessment. This can be formal tests or just a professional judgement, very often simply that the individual does not have the ability to cope in current society without help and support. This administrative categorisation as “user of the local governments’ social

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<sup>1</sup> POMONA II is a comparative international project in 14 European countries. It is funded by the European Commission of Public Health

services” is the main “demarcation” of intellectual disability today, and policy programmes are based on figures and statistics gathered according to such a definition. The definition is however far from clear and the numbers are influenced by practical circumstances. For example; during the 1990’s the system for economic transfer from state to local government was changed, and the number of people with intellectual disabilities began to play a role for the money transferred to local authorities. Thus, it was introduced a financial incentive to classify people as intellectually disabled, so to speak. This led to a 25% increase in the number of people administratively classified as intellectually disabled in Norway (from 15 400 in 1990 to 19 700 in 1998, cf. Circular I-41/95 and Circular I-16/99). It is also the case that the understanding of intellectual disability is influenced by an historical conflict of jurisdiction between health and educational authorities (in the 1950s). This conflict ended in a compromise where health authorities became responsible for people with moderate to profound intellectual disability, whereas educational authorities became responsible for people with a mild disability (IQ>50-55), called “low ability children”. This led to an understanding of intellectual disability in Norway that did not include most people with a mild disability.

## 1.2 Prevalence

The prevalence of intellectual disability will of course vary according to definitions. To our knowledge, no estimate has been made according to the relational definitions of disability. There is one study estimating the prevalence according to the ICD criteria (IQ-tests) (Strømme & Valvatne, 1998; Strømme & Hagberg, 2000). The data as gathered from 1993 to 1996 on children born between 1980 and 1985 in one Norwegian county with a population close to 400 000 (9,5% of Norway’s population). The prevalence was estimated to 0.27% with moderate to profound and 0.35% with mild intellectual disability – a total of 0.62%. This is considerably lower than most international studies on prevalence.

It is also in principle possible to estimate the prevalence from national social security records, that is, the number of people receiving any type of benefit due to intellectual disability. However, since one tend to use specific diagnosis rather than intellectual disability, such figures are likely to be vast underestimates.

The most frequently used estimate is based on the number of people that local authorities administratively have classified as intellectually disabled service users. The most recent figure available is from 2002; about 19 000 people. This is about 0.42% of Norway’s population. About 13 000 of the individuals with intellectual disability are 20 years or older, and approximately 2400 of them lived with their parents (White Paper no. 40, 2002-2003). Thus, about 2.4 per thousand of total population receive some kind of accommodation services.

## 1.3 Historical context

As in many other occidental countries, the first services specially designed for people with intellectual disability in Norway came into being in the last part of the 19<sup>th</sup> century. The first services were special schools for children. The early initiatives were private, and the schools were run as private schools with public support. Gradually the state took a more active role, and by 1901 all special schools were run by the state. Children perceived to be uneducable were not admitted to the schools, thus the system excluded most children with moderate to profound intellectual disability.

The first residential institution was established in 1898, also as a result of private initiative. This institution was given to the state as a gift in 1914. In 1917 the state opened one more residential institution, but then nothing happened for about 25 years. In 1945 there was a dramatic shortage of places both in special schools and in residential care facilities. Furthermore, the quality of the residential institutions that did exist was deemed as extremely poor. Thus, in the years

immediately after WWII, a restoration of the existing residential facilities, schools and institutions, had priority.

The 1950s and 60s was the era of expansion (cf. Table 1 and Figure 1). Number of places grew rapidly both in institutions and schools. The rationale of the 1950s was to relieve the families of the burden of their family member with intellectual disability, and the ideal service model was the large residential institution headed by medical experts. However, the new institutions were established in a partnership between the state and voluntary organisations (mostly charities); the voluntary organisation purchasing/owning the real estate and running the place while the state covered the operating costs. Money for setting up the institution was based on gifts and collection of money, and this in reality undermined the ideal of large institutions. It was easier to collect money for smaller local institutions; thus the pattern became institutions of mixed sizes – some large central facilities and a number of smaller local institutions. Special schools and the two early institutions continued to be run by the state.

*Table 1: Number of people with intellectual disabilities in residential institutions and special schools, 1945 to 1975 (Tøssebro, 1992; Statistics Norway 1994)*

	<i>Residential institutions</i>	<i>Special schools</i>	<i>Total</i>
1945/46	495	601	1096
1955/56	1538	746	2284
1960/61	2606	1252	3858
1965/66	4206	1740	5946
1970/71	5271	2206	7477
1975/76	5634	2396	8030

The 1960s was an era of transition. Evaluations concluded that there was still a dramatic shortage of places both in institutions and special schools; that the number of places only met one third of the need. Thus, the expansion program had to be intensified. But at the same time the first signs of a changing ideology emerged. Gradually the focus shifted to the quality of care. Debates were raised concerning the size of institutions, staff qualifications, custodial care, the role of the family, the relationship between special and typical education, living conditions and segregation. However, it took a while before the critical voices was transformed into an alternative ideology. Tøssebro (2003) argues that one may see the early critical voices as three partly overlapping discourses;

- the therapeutic discourse
- the welfare state discourse
- the integration/normalisation discourse

The therapeutic discourse was triggered by a renewed optimism about the learning potential of the residents. One objected to the custodial role of institutions and argued the case of more active care and a more normal environment. Some argued that the institutions themselves were intellectually disabling, but most searched for a new therapeutic underpinning of the facilities. The normalised institution became the ideal.

The welfare state discourse was actually a reaction to appalling living conditions in both institutions and residential schools. Some argued that the institutions were a way of hiding the unacceptable conditions from the public eye. Others added that one cannot expect that people can develop intellectually in such a barren environment. The debate was linked to the more general “myth of the welfare state”-debate taking place in the late 1960s. Many argued that democratic bodies had to take over responsibility for the services, and in 1970 county councils (regional government) replaced voluntary organisations as operators of residential institutions.

The integration/normalisation discourse in the 1960s was primarily about children and adults with a mild intellectual disability. The debate partly had practical roots. If one needs to triple the number of places in special schools, maybe there is a need to take a closer look at the possibilities

to integrate special education into the regular school system? And if disabled children grew up with their family, it would even be cheaper! The debate also had a highly ideological aspect linked to the international civil rights movement – the ideal behind the 1954 ruling in US Supreme Court: “Separate is not equal”. Segregation itself came to be linked to negative attitudes, apartheid etc. In special schools, the debate was quite heated for some years – and in 1967 the Ombudsman did an investigation concluding that residential schools is not a place for children to grow up.

The 1960s was an era of emerging new trends and debate, but real changes were minor. But during the 1970s and 80s things gradually began to change. The acts on special and regular education were integrated in 1975 and the local authorities became responsible for all primary and secondary education. Gradually, the state special schools were downscaled and finally closed in 1992 (except schools for deaf children). During the 1980s and 90s the inclusion ideology grew strong. Every child has now the right to go to the local school and cannot be sent to special units without parents’ consent. Special education is expected to take place within the frame-work of regular education, preferably in the class-room. In international (European) comparison, Norway is among the countries that segregate very few children (0.5% of all in 1996, cf. Vislie 2003). This does however not fully reflect the realities meeting children with intellectual disabilities. Many of the larger cities have set up their own special units; special schools or special classes in regular schools. Thus, the proportion of intellectually disabled children in regular classes varies throughout the country, and also by age/grade. According to a recent study, about 90% is included in regular child care centres (age 1-5). The figure is about 75 % in the first school year, 55% in school year 2-4, 40% in year 5-7 and 20% in year 8-10 (Tøssebro, Engan & Ytterhus, in press).

The changes in residential care in the 1970s and 80s was not, like in Sweden, characterised by a gradual resettlement from institutions. The Norwegian “deinstitutionalisation” was about making institutions less institution-like; to develop the normalised institution. The number of people in institutions peaked in 1976, but the reduction in the following decade was minor (see Figure 1). But the structure changed. Many people were relocated to small local institutions, and both the central and the local institutions grew smaller (the mean size of central institution declined from 230 in the early 1970s to about 140 in the late 1980s). Living conditions was also clearly improved during these years; for instance, dormitories were replaced by private single-person bedrooms by the end of the 1980s.

But even though the changes were significant, impatience concerning the missing resettlement from institutions, and the lack of community alternatives, grew during the 1980s. Thus in 1988, the parliament (unanimously) decided to close all institutions for intellectually disabled people, and to place responsibility for providing community care on the local authorities. The change was due for implementation from 1991 through 1995, and is often referred to as *the reform* for people with intellectual disabilities in Norway. The reform process started with a public committee report (1985, no 34) that was very critical to the current state of institutions for intellectually disabled people in Norway. They argued that;

The living conditions in the institutions were unacceptable and could not be fundamentally changed within the existing system

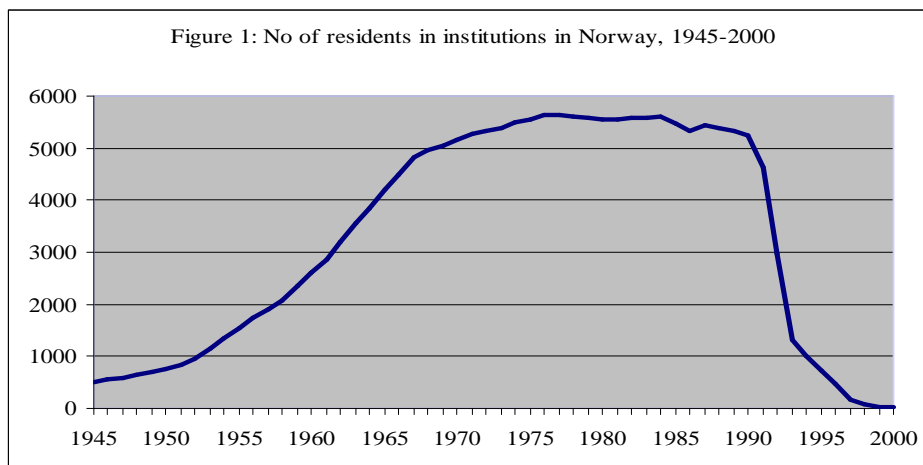
The life style in institutions is in conflict with the principles of integration and normalisation. Institutions are supposed to be specialized services, but institutions for intellectually disabled people are in reality providing ordinary care which according to the division of labour between levels of government in Norway is supposed to be the responsibility of the local government. The mere existence of institutions produced a financial disincentive for the development of community services on the part of local government.

The deinstitutionalisation in Norway was extraordinarily rapid. It started late compared to other countries, but was completed early (see Figure 1, sources: Tøssebro, 1992; Tøssebro 2003). Even though the reform was not completed according to plan by 1995, all institutions were closed

before the turn of the century. During this process, the number of people served also increased. The institutions never served more than about 1.3 per thousand of total population, whereas community care in 2001 served 2,4 per thousand. Thus, unmet demand (waiting-lists) was significantly reduced during the 1990s.

The institutions were “total” services. Thus, they were responsible for all kinds of services; accommodation, occupation, health, etc. After 1991, services should be organised according to the same principles as for the general public.

During the reform years, there was considerable disagreement on the issues of deinstitutionalisation and normalisation. However, today *the reform* has become a matter of fact and institutions considered outdated. Parents’ attitudes have changed from opposition to support (Tøssebro and Lundebj 2006). The ideals of integration and normalisation are still strong, but not that much in use in political rhetoric anymore. They are replaced by the general ideals of disability policy, originally formulated in the UN international year for disabled people (1981): equality and full participation.



### Legal rights

Any description of legal rights (rights for services and support) must take into account two very different types of rights. On the one hand people have certain individual rights. This is for example the right to education or retirement pension (apply to everyone in a certain age group), but also rights based on an assessment of individual needs, such as disability benefits or special education. On the other hand there are “rights” where access is rationed. This means that the responsible public authority has by law a duty to provide the service, but not to meet demand. If you are considered eligible for the service or benefit, you have no guarantee to have the service. It may be provided fully, short of needs or you may be referred to a waiting-list. As a consequence, one finds substantial local variation in the meeting of demand. Most social and health legislation are based on this kind of “rationed rights”.

In this section we briefly describe first individual rights and then “rationed rights” of relevance to services and benefits for people with intellectual disabilities. Meeting of demand, the real service provision is described in chapter 2 and 3.

## Individual rights

### *Social security*

The main parts of the social security system are based on individual rights, either based on the age group you belong to or because you are considered eligible based on medical conditions. The main source of income for people with intellectual disabilities is the disability benefit. In addition people may be eligible to compensation for special expenses related to the disability, certain technical aids, home adjustments and transportation (Public Committee Report No. 8, 2005).

### *Education/ special education*

All children have the right to primary (10 years, compulsory) and high school education (3 years). One also has the right to be taught according to one's qualifications and abilities. Children that according to professional assessment can not benefit sufficiently from typical education, also has the right to special education. This is an individual right, but in reality the amount of special education provided seems to be subject to procedures not very different from those of rationed services. One has the right to receive special education at the general local school, but parents can choose another school (often special classes or special schools). If a pupil needs transportation to school "because of his or her disability" this is a right regardless the distance between the school and the home (Public Committee Report No. 8, 2005).

### *Dental health*

The legislation on dental health services is the only health service which explicitly prioritizes people with intellectual disabilities. The general population have to buy dental health services themselves, whereas people with intellectual disabilities (and some other groups) have the right to free regular dentist services. Furthermore the legislation points out that the dentist service shall call upon the patients with intellectual disability and not vice versa.

### *Individual plan*

Persons with complex and long-term social and/or health needs have a right to an individual plan. This plan outlines your needs and is intended to coordinate services and identify the public agency responsible for different parts of the service provision. This right is enacted both in social and health legislation. It gives the right to a plan, but not necessarily to the rationed services involved.

### *Rights related to resettlement*

People relocated from institutions in the 1990s had a temporary right to receive services of at least the quality provided by the institutions.

### *Legal guardian/ semi-guardian*

According to the social legislation a person who can not take care of his or her own interests or needs have the right to have a guardian or semi-guardian appointed.

### *Procedures related to restraint*

During the implementation of the deinstitutionalisation reform, one saw the need for a more precise legal regulation of restraint. This is not really an individual right as such, but a regulation of the procedures service providers have to follow in order to employ restraint lawfully. The procedures are quite rigorous and are meant to protect people from the use of restraint if not absolutely necessary and to the benefit of the person.

## Rationed "rights"

### *Social services*

The local governments are obliged to offer a range of social services to the population. This is not services that the citizens as individuals have a legal right to, but everyone can apply for these

services. The services are most commonly assigned on the basis of professional assessment of the person's needs, and according to the resources of the local government. The local governments in Norway have a duty to provide the following services on such a basis;

Practical assistance and practical training in the home, including user managed personal assistant.<sup>2</sup>

- Respite care for people and families caring for family members
- Support worker/assistant (støttekontakt) to assist in social settings and leisure times
- Institution or housing with support for people that need care and support (accommodation for people with intellectual disabilities is based on this paragraph).
- Care benefit for persons with comprehensive care for family members at home
- Accommodation for people in a difficult life situation
- Support for people that cannot care for themselves

In addition to these services many local governments also provide:

Leisure time assistants who organise leisure time activities for different groups of people who needs help and support in social participation.

Day centres who provide activities and social gatherings for people who needs it.

Occupational therapy, speech therapist and psychologist

#### *Health services*

*The reform* in the 1990's implied that the responsibility for the health services for people with Intellectual disabilities where transferred from the specialised health services, that the regional governments are responsible for, to the general health services that the local governments are responsible for. This means that people with intellectual disabilities get their health services in the local community from the general health system on the same basis as everyone else. According to the patients rights legislation, every patient has the right to;

A family doctor.

Be informed about and involved in decisions regarding one owns medical treatment.

Receive information according to one owns competence.

Give ones informed consent.

Be examined within 30 days after referral.

Receive required medical treatment within 6 months after examination.

Furthermore, according to the act on community health services, local authorities are responsible for

Health care services such as a GP, physiotherapy services, public health nurse and midwife

Nursing homes and other kinds of around-the-clock nursing

Nursing at home

The services can be provided by the local authority or purchased from private providers.

Intellectually disabled people have the same right to specialized health services as any other citizen, but in each region there also exist expert teams (one for children and one for adults) expected to support local service agencies with advice and short-term support. The child teams are typically for disabled children in general, whereas the adult teams usually only provide services for intellectually disabled people. The profile varies, but child teams tend to be involved in early assessment and diagnosis, whereas the adult teams tend to work with complex needs, challenging behaviour and behavioural management.

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<sup>2</sup> This assistant is a helper that provides all the different kinds of practical help that the service user needs during the day. The important thing here is that it is the user that decides what kind of help that is needed, and when and how it is needed. This is a relatively new arrangement, established in 1994 that recently (2002) has been made available to people with intellectual disabilities.

### *Occupation/day services*

In Norway no one has a legal right to obtain work or employment, but the labour legislation has a strong intention of providing people with work or work-related occupation (Eskeland, 1992). The national Directorate of Labour is responsible for assisting people applying for work. Every local unit of the Directorate of Labour are supposed to have staff members that have a special responsibility for assisting people that are “partly” able to work, which also includes people with intellectual disabilities. People that are not seen as able to work, tend to be served by day centres. Many day centres provide work-type activities, but not all. Day centres are run by the local governments, and are not regulated by law.

## 2. SOCIAL SERVICES

In this section we will address the current pattern of social services for intellectually disabled people in Norway.

### 2.1 Eligibility

Eligibility to services is in principle the same for all citizens. It is based on the individual’s personal need for assistance, training, treatment or environmental adjustments, and is “measured” by some kind of professional assessment. Different professions can assess one person’s needs differently. Likewise will the local governments’ economic situation differ, and thus both their supply of services and their professional resources. In this respect the professional workers can feel squeezed between their loyalty to their own profession, loyalty to the service users and loyalty to their employer. All these aspects will influence on the final service provision and is a contributing factor to the variation of service provision between local authorities.

### 2.2 Service provision

#### *Accommodation/living arrangements*

The typical accommodation of adults with intellectual disability in Norway today is in a group home with 3-5 residents (mean 4.5). However, these are not traditional group-homes where people share an apartment. Each person has his or her own apartment of about 50 square meters, with a bedroom, bathroom, kitchen and sitting-room (following the National Housing Bank’s guidelines for reasonable accommodation for single-person households). Thus, the group home is a multi-apartment house (3-5 units). The apartment is typically rented from the local authority. In many cases there are also communal rooms and a staff room (outside the private apartments). Most of the houses are purpose-built and located in residential areas.

Going into detail there are some variation within this basic accommodation model. About one in five live semi-independently (apartment not in a group home). Among the group homes, a minority is traditional (people sharing the apartment, only a private room), whereas the rest is classified by whether there are communal and/or staff rooms or not. In houses with communal rooms, there may or may not be for example collective meals etc. The distribution according to a survey in 2001 is shown in Table 2 (source Tøssebro and Lundebj 2002). Note that people living with their family is excluded (18% of all aged 20 years or more, White Paper no 40, 2002-03)

Most of the people living with their family are between 20 and 30 years of age. Nearly half of the intellectually disabled people in this age group live with their family (Lundebj and Tøssebro 2002). In the general population, the corresponding figure is 22%. In about one fourth of all cases living with their family, the parents want their adult family member with intellectual disability to

be provided with to some other living arrangement, but with no acceptable alternative. Thus, there is a “waiting-list” of less than 5% of intellectually disabled people over the age of 20<sup>3</sup>.

*Table 2: Accommodation of people with intellectual disability not living with their family in 2001. Age 20-67 years. N=527*

Semi-independent living	21%
Group-home, private apartment, no communal rooms	29%
Group-home, private apartment, communal rooms	44%
Old type group home (not private apartment)	5%
Other	1%

Staffing tends to be assigned according to individual needs, and in general, people living semi-independently needs less staff than people in group-homes. They have more adaptive and less challenging behaviour (Tøssebro and Lundebj 2002). Services are provided by the local authority. In most cases the services are provided by the agency that provides home care services to all groups of service users. It is atypical to have a special agency for services to intellectually disabled people. People living with their family usually have day time occupation and respite care, but in some cases more extensive support is provided even in the family home. Staffing tends to be a mix from unqualified support workers to semi-professionals. The semi-professionals have an education that is some kind of mix between a health carer and a social worker. This education is in fact quite special for Norway and can maybe be compared to the English Learning Disability Nursing.

#### Work related and occupational services

One of the main goals in the welfare policy is to make it possible for everyone to work, so that everyone can be financially independent and provide for oneself. The welfare system is arranged to support this goal (White Paper No. 35, 1994–1995). In this regard, the situation for people with intellectual disabilities is special. The majority receive disability benefits, and will remain so. However it is still a political goal to provide work opportunities for people with intellectual disabilities. Work is seen as an important part of their lives. And most are engaged in some kind of work or work related activities.

The two main types of occupation is in sheltered work-shops and day centres. Sheltered work-shops are seen as permanent working places for people “partly” able to work, but not to be included in the open labour market. These work-shops are organised by the Labour Market authorities. According to a survey in 2001 (Tøssebro and Lundebj 2002) about 30 % of the adults with intellectual disabilities work in such sheltered work shops. This is mostly people with a mild or moderate disability. People with a more severe intellectual disability tend to be at day centres, organised by the local governments. In such centres a range of activities can take place, including work related activities. About 55 % of the adults with an intellectual disability spend parts of their day in such day centres.

The remaining 15% are either included in the open labour market (usually with subsidies) or have no day time occupation (about 10% of all adult service users with intellectual disabilities). It is a disturbing trend that the portion of people with intellectual disabilities that does not attend any kind of work or day time activities is increasing.

The goal of normalisation seems to be quite remote in the area of occupation. Only about 12% have a colleague without disabilities. Furthermore, with very few exceptions, the remuneration is only symbolic. This indicates that it is not primarily a job but rather a social event or part of social care. The goal is not to earn money but rather to structure the day, avoid passivity and

<sup>3</sup> 25% of the 18% living with their family

offer some meaningful activities. One of the most valuable roles in our society is the role of an employee, the worker and the self supporting person. The work of people with an intellectual disability, however, tends to be a fusion between work and care. As work, it has a gleam of unreality or pretence.

### Leisure time services

People who for different reasons need some support and back-up to engage in social activities in their leisure time, can receive such a service. This service is usually provided by the way of an individual assistant for one or two afternoons per week. Some communities also provide what is known as “leisure time assistants”. These assistants are not individual assistants but are group leaders that organise activities for groups of people that need adjusted leisure activities or special supervision or care in social settings. This latter service is not regulated by law and it is provided by about every fourth community (Public Committee Report No. 22, 2001). Typically people in group homes are supported in their leisure time by staff in the group home, whereas people living with their family (and some people in group homes or semi-independent living) are supported by individual assistants or “leisure time assistants”.

### Education

Some adults with intellectual disabilities receive adult education, in most cases primary education for people who have not graduated. The provision is based on “special needs”, a lack of basic skills you need to be an independent person. It can be like a minimum of reading skills, writing and talking skills, the ability to dress and take care of personal hygiene and so on. The right to receive this education as a grown-up is based on the person’s “special needs” and it does not matter what the reasons for these “special needs” are (Eskeland, 1992). Educational services for intellectually disabled people were more common in institutions, and plays only a minor role today.

The educational system for children and adolescents is briefly outlined in section 1.3: Historical context.

### End remark

The legislation that imposes the local governments to provide the different services described above, also imposes the local governments to organise and carry out these services discretionary. The services are expected to be adjusted according to the recipients needs. Different practical limitations do however turn out to play an essential role. Such limitations can be economic limitations, organizational conditions, or the caseworker’s personal competence or attitude.

## 2.3 Sources of income

The main source of income for people with intellectual disabilities is the disability benefit, which is a part of the national social security system. Among service users with an intellectual disability, only exceptional cases do not receive the disability benefit. In addition to the disability benefit, many people with intellectual disabilities receive a supplementary benefit meant to compensate extra costs due to disability or chronic illness. The actual amount of the disability benefit in Norway varies according to earlier earning and contribution time, but the rate for most people with an intellectual disability is according to regulations for people becoming disabled before adulthood. This was typically NOK 12.069 per month in 2006 (1550 Euro). There are two types of supplementary benefits. Many receive NOK 1009 per month from the one scheme and between NOK 562 and 2817 per month from the other. The variation is thus considerable and

the income can vary from only the disability benefit of NOK 12.069 per month to a total of NOK 15.895 per month. It seems that people with a more severe disability receive more supplementary benefits (Tøssebro and Lundebj, 2002).

About 50% of the people included in the 2001 survey by Tøssebro and Lundebj (2002) did also receive remuneration, though mostly symbolic. The 4% working in the open labour market had a mean annual pay of NOK 20.000, the 30% working at sheltered work-shops had NOK 12.500 annually and people in work-type activities at day centres had NOK 7.500 (22% of all). The people who receive remuneration tend to earn less in supplementary benefits, thus, if benefits and wages is added, there tend not to be any systematic differences in income between people with intellectual disabilities in Norway.

There is no official definition of poverty or poverty line in Norway, but sometimes one uses 50 per cent of the median income (mean over three years) as an indication of poverty. 50 per cent of the median income for single person households was about NOK 85.000 in 2002. People with intellectual disabilities can not be identified in the general income statistics, but compared with the data presented above; it seems unlikely that many people with intellectual disabilities have an income of less than 50% of the median. However, many have extra expenses related to health and social services and medicines. For individuals with large expenses related to disability, the consequences of a low income is regarded as far greater than for other people (White Paper No. 6, 2002-2003).

### 3. HEALTH SERVICES

As described earlier there exist no health services especially for people with intellectual disabilities, but the dental health services are obliged to prioritize people with intellectual disability and also to initiate consultations. The service is free. All other health services are according to the regular health service system (including fees and reimbursement from social security). People are expected to contact the health professional themselves and services are based on the assessment of individual needs. In the following, we will thus describe the service system and the health services most commonly used by people with intellectual disability.

#### 3.1 Current health services

The health service system is organised in two parts; the general local health services, often called primary health services (local authority responsibility), and the specialised regional health services (central government responsibility). The latter one is a supplement to the first, and may also act as a counsellor for the primary health care system.

##### Local general health services

The most common primary health services are provided by the family doctor (GP), the home nurse, the physiotherapist and the occupational therapist. You have a right to a family doctor. This is meant to facilitate continuity and stability. There is however no system of regular follow-ups or consultations. Very few doctors are directly connected to a living arrangement for people with intellectual disabilities. The services from the family doctor are as other services based on the initiative of the service user and on individual needs. There is usually little contact or collaboration between the family doctor and the rest of the service system. This may be due to the tradition in the field, work-load and/or to lack of resources. Most family doctors operate as a private business, but on contract with local authorities. Social security reimburses fees according to the general national guidelines.

Many people with intellectual disabilities also receive the services of the local home nurse, physiotherapist or occupational therapist. Services from the latter two are however less frequent, partly because of needs, but it can also be hard to obtain due of lack of supply/ resources. Some local authorities also organise services from speech therapists and psychologist. It is not mandatory for local authorities to provide these services.

Regional or national specialized health services

The back-bone of the specialised service system is the hospitals, which are run by the public (state). There do however also exist private specialised clinics. Services from the specialised health service system are based on referrals from a GP. In general, people with intellectual disabilities are referred according to health care needs, and to units providing this specific service for the whole population.

There do however also exist multidisciplinary (public) teams in each region, one for disabled children and one for adults (mainly for adults with intellectual disabilities, but not exclusively). The teams for children are involved in diagnoses, needs assessment, medical examinations and may also act as counsellors for the primary health care system, parents, schools etc. The teams tend to cooperate with paediatric units at the hospitals. In general medical services and follow-ups of children with a disability have a longer tradition and better reputation than for adults.

The profile of the teams for adults varies considerably, but tends to be counsellors for staff at the living arrangements. They tend to be involved in behavioural management for people with challenging behaviour, psychiatric problems, but also communication training etc. It is an objective that as far as possible the help from the specialized services shall be provided in the individual's home environment (White Paper No. 40, 2002–2003). The “adult multidisciplinary teams” rarely have a role in somatic health services, but may have collaboration with psychiatric units. However, the reputation of psychiatric medicine concerning people with intellectual disabilities is dubious. An investigation of the specialised services to the people with intellectual disabilities and challenging behaviour or psychiatric disorders shows huge gaps in the service provision (White Paper No. 40, 2002–2003).

There do also exist some national centres with a special role regarding people with intellectual disabilities, often by way of examinations and counselling. The most well-know in Norway is probably Frambu and the TAKO center. They are both located in the south-eastern part of Norway. Frambu specialises in rare disabilities and diagnoses, while the TAKO center are experts on complex dental health care. Furthermore there is a National Centre for Epilepsy in Sandvika nearby Oslo, which has a national role in epilepsy among people with intellectual disabilities. All these centres are national and public.

The Norwegian Board of Health conducted in 2000 an extensive survey on specialized health service provision to people with intellectual disabilities. The survey revealed that the use of specialised health services among adults with intellectual disabilities varied according to living arrangements; about like this (Norwegian Board of Health, 2000):

Living arrangement	How many receive specialized health services?
Old type group home (not private apartment)	About 70 % of the residents
Group home, private apartment, communal rooms	About 69 % of the residents
Group home, private apartment, no communal rooms	About 89 % of the residents
Semi-independent living	About 50 % of the residents

### 3.2 Body of research

Norwegian research on health and intellectual disability is quite scattered. There has so far been no systematic approach or research network on this field. There have however been some isolated studies by individual researchers. These are mainly conducted at the Norwegian University of Science and Technology in Trondheim or two Oslo-based hospitals (Rikshospitalet Universitetsklinikk and Ullevål Universitetssykehus). Research on intellectual disabilities and health has almost been a missing link in the academic medicine field at the universities. However, recently National Council for Special Education in Medicine has recognised this shortcoming.

In social sciences, research on intellectually disabilities has evolved as a more systematic academic field in the last few years. However, this research focuses on living conditions, legal rights, economic aspects, consequences of resettlement, service provision and so on. Research groups at the Norwegian University of Science and Technology in Trondheim and the Nordland Research Institute in Bodø have shown lasting interest in the subject matter. Furthermore a new national centre for service development for people with intellectual disabilities is opening this fall (2006) in Trondheim at the Sør-Trøndelag University College.

### 3.3 Life expectancy

The life expectancy in the general Norwegian population is 79.1 years; 76.4 years for men and 81.7 years for women (WHO, 2005, based on 2003 data). Since there is no official register on people with intellectual disabilities, it is impossible to single out this population in statistics on life expectancy. Thus, no reliable data on life expectancy exist. The general impression is however that life expectancy is increasing, but also that it seems shorter than for the rest of the population. This is for example suggested by the fact that a survey by the Norwegian Board of Health found that 3.7 % of the participants were 60 years or older (Norwegian Board of Health, 2000). In the general population this figure is approximately 20 % (WHO, 1999). The result may however also be a result of sampling bias or nonresponse.

### 3.4 Comparative information

There is no systematic or national health promotion, screening or gathering of statistics on the health of intellectually disabled people, only isolated efforts. The Directorate for Health and Social Affairs has recently initiated an action plan for developing a national guidance for the health care of people with intellectual disabilities. This guide will among other things address the issues of health promotion and screening.

The information about the health situation is thus poor. Public documents and reports tend to hold that there is high frequency of certain diseases among people with intellectual disabilities. This goes for example for neurological diseases, sensory impairments, and psychiatric disorders (White Paper No. 40, 2002–2003). The factual basis for this claim is however uncertain. We are unaware of any study or statistics showing the “hard facts”, not unexpected since it is not possible to identify people with intellectual disabilities in these statistics. There is however empirical experience of high incidences of epilepsy and congenital heart defects.

### 3.5 Disability specific training

The profession called “vernepleier” in Norwegian (somewhat analogous to the profession Learning Disability Nurse in the UK) is the education which is most disability specific. It is a three year college education which focuses on health and social issues of relevance to people with disabilities, and mainly people with intellectual disabilities. In other health professions it is rather accidental what kind of disability specific training the students receive, if any. In the medical

study, students have only approximately 10 hours of teaching on intellectual disabilities (Linaker and Fløvig, 2004). In Norway, intellectual disability is not recognised as a speciality in medicine. The Norwegian Medical Association has however argued for the need of a kind of formalised expertise or education in this field. Both the Norwegian Medical Association and the Norwegian Dentist Association have a special interest group for members who work with people with intellectual disabilities. Other health educations like nurses, physiotherapists, occupational therapists, speech therapists, psychologists and so on, mainly focus on the physical disabilities and only to a small degree on intellectual disabilities. Postgraduate studies in the various fields do touch upon the topic but usually it is accidental and a systematic approach is so far missing.

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