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Written Submission Regarding 2021 Day of General Discussion on Children's Rights and Alternative Care

1 Introduction

Norwegian Association for Persons with Intellectual Disabilities (NFU) is an NGO, working to realize the human rights for persons with intellectual disabilities. We promote equality and non-discrimination and advocate the rights of persons with intellectual disabilities towards local, regional and central authorities. This written submission is focusing on the situation for children with intellectual disabilities.

2 The situation in Norway

2.1 Availability of support services

In Norway, most children with disabilities live with their parents most of the time. When a child has disabilities, and the parents experience a heavy burden of care, local authorities are obligated by law, to provide the family with necessary support. Such support can be personal assistance in the family home, periodic stays in a "relief-family" or in institution, or permanent stay in institution (called child housing). Temporary stays in institutions is the most common form of support.

When deciding on what kind of support to offer a family, the local authorities must take into account what the family and the child wants, and have to emphasize their opinions and the best interest of the child, but are not obligated to accommodate their wishes. Whether the local authorities offer personal assistance in the family home, stay in relief-family or institution, or a combination, differs from municipality to municipality. The only limit is that what they offer is a sound solution for the specific family.

The challenge is that there is great variation in what is considered to be a sound solution, and there is great variation in which solutions the municipality offers. The variation is a result of local self-government, and a large amount of discretionary laws. Many families experience to be offered a service that do not fit their family's needs. Many families experience to be forced to accept temporary or permanent stay in institution against their will, otherwise they will not be provided with any support.

2.2 Quality of support services

Families who have personal assistance in their home are often very satisfied. This type of support is often organized as user-led personal assistance, where the parents decide who gives the support, when the support is given, and what the help shall consist of. Some of our members report that it can be exhaustive to have strangers/persons outside the family in their home at all times.

The experiences from families who are offered stays in a relief-family varies a lot. The quality of this support is normally dependent on how the child and the family get along with the relief-family.

Families who accept temporary or permanent stays in institutions are often left without choice. They are offered stay in institution or no relief. The Norwegian Board of Health Supervision has set some ground rules for placement, facilitation, and organization of such institutions, but local governments are often neglecting these rules. It is normal that institutions for children are placed close to, or in connection with, nursing homes. Instead of providing a family-like environment, in a normal neighbourhood, local authorities are building typical institutional buildings, with room for many children. Different children are usually placed together, without considering age, sex, interests etc. The best interest of the child, and the children's right to a family-like environment, are often given lower priority than efficiency considerations.

2.3 User-led personal assistance

The patient- and user rights act gives persons with a long-term and comprehensive service need the right to user-led personal assistance. Children, and their parent's need for relief, are covered by this right. A practical challenge is that only a service-need of 25 hours a week or more triggers the right to user-led personal assistance. Many municipalities add too much responsibility to the parent's care responsibility, arguing that the family don't meet the conditions to receive this support. The local authorities can offer user-led assistance to families who don't meet the conditions to have a right to this support, but many municipalities prefer to offer stay in institutions instead. They argue that this is less expensive. The best interest of the child, the right to respect for family life and the right to growing up in the family is rarely taken into account.

3 Measures to prevent children with intellectual disabilities being separated from their families

To prevent children with intellectual disabilities from being separated from their families, the families must be offered sufficient support services in their home. The support should be user-led, so the family can customize who, when and what the support shall consist of, individualized to the child and the family's needs. In addition to support in the family home, it should also be possible to have periodic stays in a relief-family or with relief-persons. The family should have the authority to decide which relief-family/persons they want support from.

4 Requirements to institutions, in cases where separation is unavoidable

In situations where separation from the family is unavoidable, there should be clear requirements to placement, facilitation, and organization of institutions, to ensure the children's right to grow up in a family-like environment.

Inspired by requirements set forth by The Norwegian Board of Health Supervision, the institutions should be located in a normal neighbourhood, close to schools or kindergartens, playgrounds and leisure activities. It should be facilitated as a normal house or apartment, for a maximum of 3-4 children. The children should have separate bedrooms, and the social areas should facilitate for playing and learning. The children's age, sex, interests etc. should be emphasized when placing children together. Children who need periodic stays should not be placed together with children who need permanent stay. Working shifts should be organized to create stability for the children (For example long shifts over several days. In Norway we call this "Co-living shifts".) The services should be loving and supporting and facilitate leisure activities and social activities customized for the children's wishes and needs.

These requirements should be required by law and should overrule efficiency considerations. Local authorities should be sanctioned if they don't fulfil the requirements.

5 Impact on children in institutions during covid-19 – the situation in Norway

When the covid-19 pandemic broke out, many children, and their families, were affected by strict infection control regulations. Children who had periodic stays in institutions were no longer offered to stay in the institution. The children were sent home or denied coming back. The family did not receive any compensating services in the home, leaving them with a heavy burden of care.

Children who live in institution on a permanent basis were refused to get visit from their families in the institution, or to go on short visits to their families. In this situation some families chose to take their child home, even though that meant they would be left with the responsibility for care, without support from the municipality.

Withdrawing of necessary support to families with children with intellectual disabilities represents a risk for the child. A heavy burden of care can result in exhausted parents, leaving them unsuitable to give the child sufficient care. It is likely that exhausted parents also increase the risk of violent treatment of the child, although we don't have specific knowledge of research confirming this.

Sincerely yours,

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