### MonitoringAusschuss

Unabhängiger Monitoringausschuss zur Umsetzung der UN-Konvention über die Rechte von Menschen mit Behinderungen

#### April 2025

#### Contribution

# In response to a Call for Inputs by the Office of the High Commissioner - Care and support for children with disabilities within the family environment and its gendered dimensions

#### Introduction of the Independent Monitoring Committee

The Independent Monitoring Committee is responsible for monitoring the compliance with the UN Convention "Convention on the Rights of Persons with Disabilities" (UN CRPD). It is in charge of federal legislative and executive matters. In accordance with § 13g para. 2 no. 1 and 2 BBG, the Monitoring Committee obtains statements from administrative bodies on the implementation of the UN CRPD and issue its own recommendations and opinions.

The Independent Monitoring Committee welcomes the Call for Inputs by the Office of the High Commissioner. It comments on the individual questions as follows, reserving the right to make further submissions:

#### Ad question 1

### How do societal and cultural norms and beliefs affect families of children with disabilities, particularly mothers?

In Austria, there is still a widespread social perception that disability is **something bad**.<sup>1</sup> Stereotypes that children with disabilities remain dependent throughout their lives and are a burden on their families are very prevalent in Austria.<sup>2</sup>

If it becomes apparent during pregnancy that the fetus may have a disability, medical staff and society recommend terminating the pregnancy. There is a saying in Austria "**Hauptsache g'sund**", which means "The main thing is that the child is healthy". Another saying is, "Nowadays, you don't have to have a disabled child anymore". This view is supported by the legal regulation, according to which termination is legally permitted beyond the general deadline in the event of a possible disability (see question 2).

<sup>&</sup>lt;sup>1</sup> See Federal Ministry for Women, Integration and Media, ElternTIPPs, Children with Disabilities – Advice for Special Families, 4.

<sup>&</sup>lt;sup>2</sup> See also the original case OGH 3 Ob 9/23d.

It is also suggested that the pregnant person may have done something wrong before or during pregnancy that caused the disability.

When a child is born with disabilities, their life is often marked by **segregation**. There is still a widespread belief that people with disabilities need to be treated in a very special way that excludes them from the rest of society. There is often a very specific path mapped out for children with disabilities: attendance at a special needs kindergarten, followed by a special school. Special schools are also offered with boarding facilities for children from the age of six.<sup>3</sup> In addition to the education system, leisure activities for children and young people are also not inclusive in most cases. This means there is no or little inclusion after kindergarten or school. Children with disabilities therefore often grow up in isolation, without contact with children of the same age without disabilities.

In Austria, politicians often emphasize the "**right of parental choice**". This means that parents should have the choice of sending their child to a mainstream school together with children without disabilities or to a special school only for children with disabilities. It should be emphasized here that the "right of parental choice" cannot be consistent with the UN CRPD because the right to education always lies with the child and therefore the child must have the right to choose which school to attend. Furthermore, it is often not possible to speak of free choice. In some cases, there is no real possibility of attending a mainstream school. For example, the only accessible school transport services are exclusively for special schools, or no assistance is provided in mainstream schools. In many cases, inclusion in mainstream schools is also not a reality. Children with disabilities are unable to participate in all lessons, and there was a case where a child with disabilities has been forced to sit in the school corridor instead of in the classroom.

On the other hand, the segregating institutions themselves are in some cases very well equipped, integrating easily accessible therapy programs into the daily routine or providing barrier-free premises and well-trained staff.

This means that parents or children themselves often have no choice.

Politicians themselves sometimes explicitly state that certain children with disabilities have a "greater need for care and support than for schooling".<sup>4</sup> This completely denies the human right to education for children with complex care needs. The commitment to segregation or general exclusion from the education system is firmly entrenched in

https://mariatal.tsn.at/ueber-uns-leitbild.

<sup>&</sup>lt;sup>3</sup> See MARIATAL State Special School with Boarding School, Mission Statement,

<sup>&</sup>lt;sup>4</sup> FPÖ and ÖVP; Strong Styria. Secure Future,

https://media.steiermark.at/flexpaper/Regierungsprogramm/index.html.

almost all political parties in Austria. Even the federal government has been unable to bring itself to commit to a determined dismantling of special schools.<sup>5</sup>

Due to a lack of other support, children with disabilities are usually heavily **dependent on their caregivers** and often remain within the family unit without being able to develop a circle of friends with children of the same age. This also makes it more difficult for them to establish an independent life outside the family in adulthood. Because there is no inclusive education and care system for children with disabilities, families are often faced with the decision to place their child in an institution or provide full care at home by a family member. As Austria continues to be shaped by the patriarchal view that women are responsible for caring for the family, it is usually the **mother** who stays at home with the child and cares for them.<sup>6</sup>

This means that income is lost, which leads to a precarious situation for the family in general. State social benefits are available, but they are often tied to specific purposes and vary from region to region (see question 4).

Reducing working hours or leaving work has adverse **career and financial consequences** for mothers. This increases their dependence on the parent earning an income.

### Ad question 2

### Experiences and support for parents during pregnancy and birth of a child with disabilities.

During pregnancy, Austria provides a "parent-child health passport." This requires mandatory preventive medical checkups for pregnant person. These checkups determine whether the fetus may have any disabilities. If a disability is considered possible, the pregnant person may **terminate** the pregnancy beyond the first three months (§ 97 para. 1 no. 2 StGB). Otherwise, this is only possible if the pregnant person was under 14 years of age, or their health is at risk.

If the pregnancy is continued despite a possible disability, more intensive **medical** care is provided. Counseling by a self-help group is possible but not mandatory and always depends on the services available in the region.<sup>7</sup> A brochure on prenatal diagnostics lists possible "forms of support" for families with children with disabilities: family assistance (see question 5), short-term accommodation for up to four weeks per year,

<sup>&</sup>lt;sup>5</sup> ÖVP, SPÖ and Neos, Doing the right thing now. For Austria. available at

https://www.bundeskanzleramt.gv.at/bundeskanzleramt/die-bundesregierung/regierungsdokumente.html. <sup>6</sup> Federal Ministry for Women, Integration and Media, ElternTIPPs, Children with disabilities – Advice for special families, 13 f.

<sup>&</sup>lt;sup>7</sup> See Family counseling, Disability, https://www.familienberatung.gv.at/themenartikel/Behinderung.html.

placement in an institution or foster care.<sup>8</sup> It should be noted that two of the four forms of support involve the long-term removal of the child from their family of origin.

### Ad question 3

### Availability and accessibility of early identification and intervention, and early childhood care and development for children with disabilities.

When a child is born with disabilities, an assessment is made during the birth to determine the child's likely development and to decide on therapies such as medical treatment.

If a disability is only discovered later, it is assessed by a pediatrician and specialist at a later date. The stated goal is early and targeted support. Each federal state has its own procedures and clinics for developmental diagnostics.<sup>9</sup>

**Early intervention** is a general term for all services offered to young children and their families. This includes services in the fields of psychology, medicine, social work, psychotherapy, speech therapy, music therapy, and special education.

The services available **vary** from federal state to federal state and are provided by different organizations. The Offices of the Social Services Agency provide children and their families with information about available support and refer them to the responsible regional agencies and organizations.<sup>10</sup>

The differences between the federal states are very distinct. For example, in Styria, early intervention is available until the start of school at age six,<sup>11</sup> while in Salzburg, this support is available until age four.<sup>12</sup> In addition, the applicable definitions of "disability" in the federal states' disability laws, which vary greatly, must be met in order to access services.

The services offered for early intervention also vary depending on the federal state and

<sup>&</sup>lt;sup>8</sup> City of Vienna, Prenatal Diagnostics – Examination during Pregnancy, https://www.wien.gv.at/gesundheit/beratung-vorsorge/frauen/frauengesundheit/pdf/praenataldiagnostik.pdf.

<sup>&</sup>lt;sup>9</sup> oesterreich.gv.at, Early detection of disabilities,

https://www.oesterreich.gv.at/themen/menschen\_mit\_behinderungen/kindheit\_und\_behinderung/4/Seite. 1220100.html.

<sup>&</sup>lt;sup>10</sup> oesterreich.gv.at, Early intervention,

https://www.oesterreich.gv.at/themen/menschen\_mit\_behinderungen/kindheit\_und\_behinderung/2/Seite. 1220210.html.

<sup>&</sup>lt;sup>11</sup> The State of Styria, Education and Schooling, https://www.verwaltung.

steiermark.at/cms/beitrag/12540972/127384147/#:~:text=Fr%C3%BChf%C3%B6rderung%20bekommt%2 0man%20bis%20zum,3%20Monate%20nach%20dem%20Schulbeginn.

<sup>&</sup>lt;sup>12</sup> Center for Development Support, Early Intervention, and Family Support, https://ambulatoriumsalzburg.at/fruhforderung-und-familienbegleitung/.

region. The services available also vary depending on where you live.<sup>13</sup> It should be noted that the support services are not always clearly distinguished from one another. For example, early intervention services also have parallels with family support (see question 5).

Applications for the **procedure** for obtaining early intervention must usually be submitted in advance. Invoices cannot be accepted retrospectively. The child and youth welfare service, the district administrative authority or other agencies may be responsible. It should also be noted that costs may be incurred for early intervention.

### Ad question 4

# Challenges and good practices in family, child, gender equality, and social protection laws and policies, including those addressing the gendered aspects of caregiving and support and those formalising family care and support (e.g. through pensions, allowances, etc.).

In addition to support in the form of services such as early intervention and family assistance (see questions 3 and 5), financial assistance is also available.

Financial assistance is divided into medical measures, the purchase of aids for social rehabilitation, home modifications, and other social services. There is compensation for families and support from a public fund and private associations. There is care allowance, increased family allowance, school travel allowance, reimbursement of therapy costs, reimbursement of travel costs for therapy, subsidies for car conversions, etc. There are also fee exemptions and reductions as well as tax relief.<sup>14</sup> Financial assistance is available from several sources and can be confusing.

The Independent Monitoring Committee is not aware of any best practices that address gender-specific aspects of care and support.

### Ad question 5

Information, support, and services available to enable families to meet their care and support responsibilities towards children with disabilities while respecting their rights and evolving capacities (e.g. access to inclusive education, quality healthcare,

<sup>&</sup>lt;sup>13</sup> The Diakonie's early intervention program for the state of Upper Austria includes therapeutic vaulting, therapeutic climbing, social skills training, and music and dance therapy. Diakonie, Services and Facilities, https://www.diakonie.at/unsere-angebote-und-einrichtungen/liste?

type=list&address=Linz&distance=20&text=&topic\_offer\_type%5B221%5D%5B0%5D=1608&topic\_offer\_type%5B221%5D%5B1%5D=1684.

<sup>&</sup>lt;sup>14</sup> Ministry of Social Affairs, Financial Support, https://www.sozialministeriumservice.

at/Menschen\_mit\_Behinderung/Finanzielle\_Unterstuetzung/Finanzielle\_Unterstuetzung.de.html#; oesterreich.gv.at, Financial support,

https://www.oesterreich.gv.at/themen/menschen\_mit\_behinderungen/kindheit\_und\_behinderung/1.html.

### rehabilitation, assistive devices, personal assistance, housing adaptation, respite care, peer-to-peer and community networks, psychosocial support, etc.).

#### Regarding access to inclusive education:

As mentioned in question 1, inclusion is a very difficult issue in Austria. Children with disabilities are strongly pushed into segregated educational institutions, such as special needs kindergartens or special schools.

This was also noted by the UN Committee, which called for an end to the expansion of the segregated school system and for resources to be directed toward inclusive education instead.<sup>15</sup> In the NAP Disability, with which the Republic of Austria intends to implement the UN CRPD, among other things, the Ministry of Education states that the path toward an inclusive education system should be continued and that it is committed to an inclusive teaching and learning culture. A nationwide strategy for inclusive education is to be developed. This strategy must cover all levels of the education system.<sup>16</sup>

In federal educational institutions, an improved decree from 2023 applies to support students.<sup>17</sup> This decree provides for different forms of support depending on the individual situation and takes into account the journey to school and (multi-day) school events. Support services can include personal assistance, school assistance, and interpreting services. It is essential that all children with disabilities, and not just those with physical or sensory impairments, are able to receive personal assistance. However, this only applies to federal educational institutions.

Large areas of education are the responsibility of the federal states. Each of the nine federal states and the federal government can therefore regulate their own education system. This means that there are ten different systems in Austria. The forms of support also vary considerably as a result.

### Regarding home modifications:

There are aids available for home modifications (see question 4), but barrier-free housing construction in Austria is generally in decline. The UN expert committee has also noted this with concern and recommended significant improvements in accessibility.<sup>18</sup> But the latest developments don't show any improvements. A new draft

<sup>&</sup>lt;sup>15</sup> CRPD/C/AUT/CO/2-3\* Rz 57 f.

<sup>&</sup>lt;sup>16</sup> See ÖBR, press release: Human right to inclusive education,

https://www.behindertenrat.at/2024/01/menschenrecht-auf-inklusive-bildung/. Ministry of Social Affairs, National Action Plan on Disability 2022-2030, 75 ff.

<sup>&</sup>lt;sup>17</sup> GZ: 2023-0.480.776. The background to this decree was the class action lawsuit for inclusive education, which the Ministry of Education lost: Bizeps, Ministry of Education responds to lost class action lawsuit with new decree, https://www.bizeps.or.at/bildungsministerium-reagiert-mit-neuem-erlass-auf-verlorene-verbandsklage/.

<sup>&</sup>lt;sup>18</sup> CRPD/C/AUT/CO/2-3\* Rz 27 f.

law in the federal state of Salzburg plans further reductions in accessibility in new buildings.

### Regarding Healthcare:

Healthcare in Austria faces a number of challenges. There are initiatives aimed at improving accessibility in certain clinics. However, there are differences between clinics and between practices. As healthcare is also part of the remit of the federal states, there are also significant differences in the legal situation and the resulting rights.

### Regarding support services:

Support services are primarily a federal state matter, which means that there are significant differences in the type and scope of services available across Austria. In all federal states, support services are only available with a referral from the child and youth welfare agency, and in most cases, there is no legal entitlement to such services. The support available therefore varies from federal state to federal state and from agency to agency. In addition, these services consist of individual care and family-based assistance. They are not inclusive services where children with and without disabilities come together. Inclusion cannot therefore take place in these forms.

One possible form of support is **family assistance** for families with children with disabilities. This is offered by various providers, such as Caritas family assistance in Vienna. It is a mobile service that provides support for caring for the child at home within the family and usually lasts up to six months. It is a form of help for self-help.<sup>19</sup>

A slightly different option is **family support**, which is offered by organizations such as Diakonie. This also involves mobile care at home. The main focus is on caring for children with disabilities after kindergarten or school.<sup>20</sup>

The **family relief service**, offered by Malteser Care, for example, is again slightly different. Families receive up to four hours of support at home per week.<sup>21</sup>

Other forms of support mentioned, which involve placing the child in care, are not discussed here (see question 2).

### Regarding peer-to-peer and community networks:

Peer counseling services exist in Austria. However, these are only offered by individual organizations and are mostly designed as projects without secure long-term funding.

<sup>&</sup>lt;sup>19</sup> Caritas, Family assistance in child and youth welfare, https://www.caritas-steiermark.at/hilfeangebote/familien-frauen/familienleben/familienhilfe-in-der-kinder-und-jugendhilfe.

<sup>&</sup>lt;sup>20</sup> Diakonie, Family support at home, https://www.diakonie.at/unsere-angebote-und-einrichtungen/fabi-familienbegleitung-fuer-kinder-und-jugendliche-mit-behinderung-durch-inklusion

<sup>&</sup>lt;sup>21</sup> Maltester Care, Relief services for families, https://www.malteser.care/leistungen/entlastungsangebote-fuer-familien/.

They are primarily aimed at parents with children with disabilities and not at the children themselves.<sup>22</sup>

### Ad question 6

### Continuation and evolution of services and support along the lifecycle, particularly as children with disabilities reach adulthood and older age.

The continuation of services and projects presents a problem. Young people with disabilities receive support that varies greatly from case to case. However, many services have a maximum age limit, such as the age of majority. Once this age is reached, the person can no longer use the service and must find another form of support.

### Ad question 7

# How are families and persons with disabilities, including children, consulted on laws, policies and measures concerning care and support, including in the family environment.

In some cases, people with disabilities are involved in the development of health policies or draft legislation. However, the Independent Monitoring Committee is not aware of any standardized participation procedure. It is considered doubtful that children, especially children with disabilities, have the opportunity to participate in matters that affect them.

### Ad question 8

# Availability and analysis of data on the needs and existing support to families of children with disabilities, including specifically on gendered aspects of care and support.

In the area of education, data is available on children who attend special schools or are taught according to special school curricula. Otherwise, the Independent Monitoring Committee is not aware of any data on forms of support for families with children with disabilities.

<sup>&</sup>lt;sup>22</sup> Children's network, Peer counseling, and transition coaches, https://www.kindernetzwerk.de/de/lotse/aus-erfahrung-klug.php.

### Ad question 9

Conduct of time-use and care surveys, and inclusion and results of questions related to the disability status of people providing and receiving care and support and people involved in self-care.

The Independent Monitoring Committee is not aware of any such circumstances.

For the Committee

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