

Executive Summary of 2nd Global Report on the Situation of Persons with Deafblindness

Good Practices and Recommendations for the Inclusion of Persons with Deafblindness March 2023

Introduction

Deafblindness is a distinct disability arising from a dual sensory impairment that makes it hard for the impaired senses to compensate for each other. This impairment affects communication, access to information, orientation, and mobility. Persons with deafblindness make up 0.2% to 2% of the population and are one of the most marginalised and excluded groups. These individuals require accessibility measures, reasonable accommodation, and access to specific support services, such as interpreter-guides/Deafblind interpreters and assistive devices and technologies, to overcome significant attitudinal, environmental, and institutional barriers.

Building on the success of its <u>first global report on the situation of persons with deafblindness</u>, the World Federation of the Deafblind (WFDB) embarked on this second global report, shifting the dialogue to identify good practices and practical recommendations to improve social inclusion. Additionally, this second report includes case studies to illustrate and inspire change to improve implementation of the Convention on the Rights of Persons with Disabilities (CRPD) and the Sustainable Development Goals (SDGs). This report provides a quantitative analysis of data on children with deafblindness. It aims to serve as an advocacy tool for WFDB members and allies and to inform governments, donors, non-governmental I organisations (NGOs), organisations of persons with disabilities (OPDs), service providers, frontline staff, and inter-governmental organisations (IGOs) on how to foster the inclusion of persons with deafblindness.

Quantitative analysis on the prevalence and experience of children with deafblindness was conducted by the International Centre for Evidence in Disability (ICED) using data on children aged 2-17 across 36 countries from UNICEF's Multiple Cluster Indicator Surveys (MICS). The prevalence of deafblindness in children across these 36 countries is reflected in the table below, totalling 1,842,145 children across the 36 countries.

Severe deafblindness	0.05% or 1 out of 2,000 children
Moderate deafblindness	0.14% or 1 out of 700 children
Mild deafblindness	0.70% or 1 out of 140 children

Qualitative research involved a literature review, a survey of WFDB members and practitioners, and key informant interviews to develop case studies to identify the main factors of good practices in line with the CRPD. The findings of the research are organised into two sections, following a twin-track approach:

1. Preconditions for inclusion

- Deafblindness as a distinct disability
- Tackling stigma and discrimination
- Accessibility
- Disability-specific services, including deafblind-specific services
 - o Identification, assessment, and referral
 - Rehabilitation and communication
 - Assistive devices and technologies and accessible technologies
 - Interpreter-guides/Deafblind interpreters and other forms of live assistance
- Participation of persons with deafblindness
- Data collection and research

2. Disability mainstreaming of laws, policies, and services

- Inclusive education
- Health
- Work, employment, and technical and vocational training
- Social protection
- Participation in public and political life
- Recreation and participation in social life
- Preventing and responding to violence, abuse, and exploitation
- Response to emergencies.

1. Preconditions for Inclusion

The twin-track approach for disability inclusion requires disability-specific measures through programming, policies, procedures, etc., to meet the requirements of persons with disabilities as well as consistent, systematic mainstreaming of disability across all programmes, policies, and processes. Preconditions for disability inclusion are the prerequisites or measures that are commonly required by persons with disabilities. This report focuses on the preconditions for persons with deafblindness.

Deafblindness as a Distinct Disability

Legal recognition of deafblindness as a unique disability is often the first step to addressing social exclusion. There is a direct link between the legal recognition of deafblindness and the availability of deafblindness-specific supports and services. The best way to ensure deafblindness is officially recognised is through national disability legislation that lists the types of disabilities covered by the law. However, depending on the legal system, additional legislation, policies, plans, and services should

recognise deafblindness as a distinct disability, and not a combination of blindness and deafness, and share a common definition in line with the Nordic Definition of Deafblindness.

Tackling Stigma and Discrimination

Exclusion of persons with deafblindness often stems from discrimination and stigma based on misperceptions or lack of understanding about persons with deafblindness. A common misperception is that persons with deafblindness cannot be helped, supported, or reached due to their high-support requirements and communication barriers. This has led to extreme exclusion, even among persons with disabilities. Moreover, these individuals often experience multiple and intersecting discrimination across two or more characteristics, e.g., gender, age, ethnicity, etc. Reasonable accommodation is one of the most effective tools to tackle discrimination and stigma, which often involves interpreter-guides/Deafblind interpreters, information in accessible formats, assistive devices and technologies, and adjustments to procedures. Targeted awareness-raising through campaigns, training, media, support groups, information resources, and other avenues can effectively address discrimination. Awareness-raising should involve persons with deafblindness, promote positive portrayals of persons with deafblindness, and consider the sustainability of efforts to ensure systemic institutional learning.

Accessibility

Persons with deafblindness experience barriers to communication, information, orientation, and mobility in public spaces. While they may share some accessibility measures with people who are deaf and people who are blind, they are a distinct group requiring different levels of accessibility. Common elements for the built environment to improve accessibility include illumination, contrasting colours, colour coding or visual/textual cues, glare reduction, large font / Braille signage, loop induction systems, vibration devices to help with orientation, use of sound to reduce ambient noise, material finish, and physical accessibility supports, such as handrails, level surfaces, etc. Information, communication, and accommodations at events may involve Braille, large print, audio description, "Easy Read" or other summary versions, captioning, sign language interpretation, speaking one at a time, providing a name before speaking, allowing time for translation, regular breaks, making the speaker's face visible, explaining visual aids, visual aids with high contrast, sending documents in advance, and providing notes to sum up events.

Disability-specific Services

These may be organised or arranged in different ways and should be embedded within mainstream services and include:

- Identification, assessment, and referral services
- Rehabilitation services
- Deafblind support services, more specifically, access to interpreterguide/Deafblind interpreter services or other forms of live assistance, such as personal assistants or caregivers.

Where countries lack technical expertise on these services for persons with deafblindness, they should look to a 'standout organisation' or develop a cross-border network of OPDs, parents' groups, research centres, and service providers to serve as the driving force in establishing a resource centre or hub on deafblindness. These centres should gather and provide information and technical resources to persons with deafblindness, families, and practitioners across a range of services, such as a resource library, online repository, training courses and links with technical experts. In addition, disability-specific services, including deafblind-specific services should be available throughout the country.

a) Identification, Assessment, and Referral

Deafblindness is not necessarily easy to detect, and misidentification is common in both children and adults. Identification can be managed through risk factor questionnaires and/or health checks to screen for vision and hearing. Infants and children are at risk of developmental delays if deafblindness is not identified early, requiring more significant interventions later in childhood. Regardless of their age, people who are flagged for risks during screening should be referred to intervention specialists, which is usually an interdisciplinary team that performs additional testing and rehabilitation services. Assessments should be based on the latest research and experience within the field of deafblindness across a range of functional areas, e.g., hearing, vision, orientation, mobility, and cognition, based on established professional standards. Referrals should also include information on benefits, social protection, and information and advice for individuals and families.

b) Rehabilitation and Communication

Without rehabilitation and habilitation services, persons with deafblindness may struggle to perform daily activities. Additionally, many do not learn how to fully communicate or rely on a type of 'home sign' that only a few understand, such as immediate family. For many individuals, community-based rehabilitation (CBR), also known as community centred rehabilitation, which is a cross-disciplinary, crosssectoral model for delivering health and social service through hospitals, schools, clinics, the home, and businesses is the best option for successful rehabilitation. These services form part of Universal Health Coverage and are essential to persons with disabilities. For persons with deafblindness, CBR must be flexible, personcentred, supporting the requirements of the individual through various stages of life adjustment with autonomy and independence at the heart of the service. Good practices involve developing an individual plan exploring everyday survival, life adjustments, new ways to cope, communication methods, orientation, mobility, stabilising strategies, life goals, new routines, and emotional factors. CBR services should set the focus based on the age and development of the individual, and social inclusion should be integrated into strategies for developing communication methods.

c) Assistive Devices and Technologies and Accessible Technologies

Assistive devices and accessible technologies help improve functioning and independence to aid in communication, information, mobility and/or memory. However, these products are often unavailable or unaffordable in many countries. To improve access and affordability, persons with deafblindness should be involved in

identifying their needs and policies should identify minimum standards to ensure persons with deafblindness are able to access assistive products. Moreover, priority products should be identified, production and procurement support should be considered, the provision of assistive products should be free and affordable with easy access to services, and professionals should be trained on how to support persons with deafblindness who are using assistive products. In addition, the maintenance, repair, and updating of assistive devices and technologies should be continuous. International cooperation and technical assistance between countries should be encouraged to share information and good practices on assistive products.

d) Interpreter-guides/Deafblind interpreters and Other Forms of Live Assistance

Persons with deafblindness may require live assistance to support independence, autonomy, and inclusion in the community. Most commonly, they may require interpreter-guides/Deafblind interpreters, or trained professionals that are responsive to their specific and individual requirements including communication, interpretation, access to information, description, orientation, guiding, and mobility support. However, other live assistants, such as teaching assistants, carers, personal assistants, etc., may be required. Services for the deaf or blind are insufficient for persons with deafblindness. Interpreter-guide/Deafblind interpreter services are not widely available or affordable, forcing many to rely on family or friends or to simply do without. Despite the lack of availability, these services are essential and form an immediate obligation on States. Essential elements for interpreter-guide/Deafblind interpretation services include guidelines for technical and behavioural competencies, a training and certification programme, a role profile and fair compensation, a registry and booking system, quality control measures, and a professional body. These services should be available and accessible across the country with concrete, progressive steps to make them affordable, e.g., through publicly funded free services, and OPDs of persons with deafblindness should be directly consulted in the development of these services. A global mechanism to systematically address gaps in live assistance for all persons with disabilities, including interpreter-guides/Deafblind interpreters for persons with deafblindness, could generate momentum that OPDs of persons with deafblindness may not be able to achieve on their own.

Participation of Persons with Deafblindness

Persons with deafblindness and their representative organisations or OPDs should be involved in decisions about resources and accommodations. This often does not happen because of a lack of sufficient accessibility measures and reasonable support. accommodation. such as communication including guides/Deafblind interpreters and accessible information, and the misperception that it is too difficult for them to participate. In low-income countries, economic barriers result in persons with deafblindness being preoccupied with income-generating activities, reducing their participation in other aspects of society. Many OPDs of persons with deafblindness lack the capacity and resources to engage in decisionmaking processes, but there is a systematic exclusion that goes well beyond these challenges. Persons with deafblindness should be actively invited to join processes where decisions about them are made, provided with a guarantee of reasonable accommodations, access to information and communication support (e.g., interpreterguides/Deafblind interpreters). It is important that these individuals are given time to provide input, and allowed other adjustments, as needed. The costs of interpreter-guides/Deafblind interpreters should be covered by the organisers of the participatory process, and accessibility and inclusion should be a cross-cutting requirement of all participatory processes. The value and capabilities of persons with deafblindness should be recognised. OPDs of persons with deafblindness should maintain autonomy over decisions in joint programmes and projects, and proxies or substitute representatives without deafblindness should not be used without the express consent of persons with deafblindness. Finally, governments should address the extreme poverty of persons with deafblindness so that they can focus their attention on participatory processes and opportunities.

Data Collection and Research

Persons with deafblindness are often invisible in statistics and research that could aid decision-makers with the planning and budgeting necessary to accommodate their unique needs. Statistical data using the Washington Group Questions can be analysed using three prevalence thresholds in large surveys:

- 1. Severe 'A lot of difficulty' or 'cannot do' for both vision and hearing
- 2. **Moderate** 'A lot of difficulty' or 'cannot do' in either vision or hearing and at least 'some difficulty' in the other domain
- 3. **Mild** 'Some difficulty' in both vision and hearing.

Greater international cooperation is needed to formulate a qualitative and quantitative research agenda with persons with deafblindness and OPDs identifying the key priorities. In addition, they can be involved in all stages of research if properly supported. A top priority is to develop research and evidence on the effectiveness of models or services that maximise their independence and autonomy and improve the quality of life in line with the CRPD.

2. Disability Mainstreaming of Laws, Policies, and Services

Persons with deafblindness should have access to the same mainstream services as persons without disabilities, such as education, employment, social protection, recreational facilities, voting, vocational training, and more. Disability mainstreaming involves a focus on particular groups, including persons with deafblindness, to ensure they are included and not segregated. Mainstream services should link with the preconditions for disability inclusion, e.g., identification, assessment, and referral; rehabilitation and communication; interpreter-guide/Deafblind interpreter services; access to assistive devices; accessibility measures; and more, to facilitate the inclusion of persons with deafblindness.

Inclusive Education

Many children with deafblindness are not enrolled in school, and often segregated education or 'special schools' are the only option available to them. Analysis from 36 countries in the MICS data revealed the following figures regarding education enrolment:

Children aged 3-4 in early childhood education programmes	
Children with deafblindness	7%
Children with other disabilities	20%
Children without disabilities	31%
Children in primary school	
Children with deafblindness	20%
Children with other disabilities	66%
Children without disabilities	75%
Children in secondary school	
Children with deafblindness	16%
Children with other disabilities	36%
Children without disabilities	49%

The MICS data also demonstrated that children with deafblindness aged 3-4 years were nearly half as likely to be developmentally on track, according to the Early Childhood Index, compared to children with other disabilities and three times less likely compared to children without disabilities.

Many countries are transitioning from segregated education to inclusive education models in mainstream schools. However, placing children with deafblindness in mainstream schools without the appropriate support is not inclusive education. They require rehabilitation services and support to develop the ability to communicate, perform basic life skills, facilitate orientation and mobility, and develop social skills. Education must be delivered in modes and means of communication for the individual. Additionally, adapted teaching practices, such as adopting a bilingual framework, can ensure the social and cultural development of children with deafblindness is maintained in respect to their language, especially for sign language users. Early identification and referral programmes are critical for improving educational, cognitive, and social outcomes for children with deafblindness and should be integrated into early education programmes. Community-based programmes, i.e., a type of home schooling with quidelines and support from trained special education teachers and an adapted curriculum, can help to support these children to enable them to become school-ready and to develop essential life skills where early education programmes and rehabilitation services are in short supply.

Key elements for ensuring inclusive education for children with deafblindness include identification, assessment and referral services; rehabilitation services; access to assistive devices and technologies; adaptation of the curricula; individualised education plans; sensitisation and training for teachers and staff; accessible learning materials; provision of live assistance or teaching assistance to aid communication and learning; sensitisation of parents and the community; and regular data collection. Where educational opportunities were missed by adults with deafblindness, learning programmes for adults to fill educational gaps, e.g., to gain qualifications or learn basic skills, should be provided.

Health

Persons with deafblindness often require more health care but experience high levels of exclusion due to a lack of understanding among health professionals of

deafblindness, related health conditions, and risk factors. There is emerging evidence that these individuals are also at increased risk of mental health conditions due to isolation and lack of social support. Data from 36 countries in the MICS showed that children with deafblindness have poorer health outcomes. The data revealed that in the last two weeks, children with deafblindness aged 2-4 years were 20% more likely to have acute respiratory infection, 48% more likely to have diarrhoea, 22% more likely to experience wasting, and 24% more likely to have stunted growth compared to children without disabilities. However, they were equally likely to have access to health insurance compared to other groups, indicating that the quality of care is a significant concern.

Persons with deafblindness should be identified as a priority group with increased risks of developing other health conditions, and health services should link with disability-specific services, e.g., rehabilitation services and access to assistive devices and technologies. To make mainstream services inclusive for persons with deafblindness, the following elements should be adopted: training and sensitisation of health care staff, the establishment of a deafblindness team within the health system, linkages with interpreter-guide/Deafblind interpreter services, access to health information and communication aids (e.g., personalised cards or alerts on medical records on communication requirements), access to mental health screening and services, and measures to prevent family members serving as proxies.

Work, Employment, and Technical and Vocational Training

Persons with deafblindness are often excluded from work and vocational programmes due to misperceptions about their capabilities, lack of reasonable accommodation, and lack of interpreter-guide/Deafblind interpreter services. These individuals are often only supported through sheltered workshops or ineffective programmes to support work in the informal sector. Governments, employers, and other development actors should be encouraged to support mainstream, waged employment of persons with deafblindness rather than self-employment in the informal economy or segregated or sheltered workshops. The elements for achieving this include access to quality, inclusive education; strong anti-discrimination laws and policies to require employers to provide reasonable accommodation; affordable interpreter-guide/Deafblind interpreter services; access to assistive devices and technologies; national accessibility standards and guidelines for employers; linkages between rehabilitation services and employment programmes; training for employers, families, vocational training providers, government, and other stakeholders to tackle stigma and promote the capabilities of persons with deafblindness; inclusive, mainstream technical and vocational education programmes with access to teaching assistants; and access to banking and other financial services. Self-employment should be freely chosen, and entrepreneurial programmes should be aimed at the formal labour market instead of the informal sector. In addition, family members who care for persons with deafblindness should be given support to transition into work to boost the overall economic empowerment of families but also to recognise the distinct needs of carers as well as persons with deafblindness in seeking employment.

Employers should take steps to make workplaces more inclusive for persons with deafblindness by providing sensitisation training for staff, reasonable accommodation policies and procedures, accessibility standards, a more flexible work environment,

and internal mentors or peers to support social inclusion. OPDs of persons with deafblindness can provide technical support and advice to employers to help them understand the requirements of persons with deafblindness.

Social Protection

A household with a person with deafblindness affects the whole family, especially where there are limited supports in the community. Data from 36 countries in the MICS showed that children with deafblindness were 30% more likely to live in poverty compared to children without disabilities in upper-middle-income countries. This is partly due to the extra costs of having a disability to pay for interpreter-guides/Deafblind interpreters, assistive devices, accessible transport, adaptations to the home, hired caregivers, health and rehabilitation services, tuition or tutors that are not provided through public funding, and more. In addition, to be eligible for social protection schemes, it is often required to provide proof of identification as well as proof of disability. Data from the MICS in 36 countries showed that half of the children with deafblindness aged 2-4 years had their birth officially registered compared with 61% of children with other disabilities and 73% of children without disabilities, which can be a barrier to accessing social protection.

The first step to ensuring the right to an adequate standard of living for this group is legal recognition of deafblindness as a distinct disability, which enables targeted, tailored interventions for the group. Other good practices for ensuring access to social protection include a holistic, targeted approach for households with persons with deafblindness, specific guidance and training for social workers on persons with deafblindness, consideration of the poverty-related aspects of persons with deafblindness (such as the extra costs of having deafblindness), linkages between mainstream and disability-specific services to address poverty concerns, accessible information on social protection supports and eligibility guidelines, removal of administrative barriers (e.g., improved access to identification card systems), and improved data collection to inform planning.

Participation in Public and Political Life

To ensure persons with deafblindness can participate in voting, accessibility measures should be adopted, and reasonable accommodations should be provided. This may involve guidance on the requirements of persons with deafblindness for election officials and poll workers, access to interpreter-guide/Deafblind interpreting services, opportunities to observe the accessibility of voting processes, accessible information and materials (including on candidates or parties), and accessible polling sites, voting machines, and ballots. For persons with deafblindness to serve as elected or appointed representatives, governments should adopt reasonable accommodation policies and procedures, including access to interpreter-guides/Deafblind interpreters and accessible technologies, to facilitate their participation. Representation of persons with deafblindness should reflect their diversity of gender, age, communication preferences, and other aspects.

OPDs of persons with deafblindness are a good vehicle for facilitating political participation of persons with deafblindness, but they face significant barriers, often struggling to operate consistently. To support their functioning, barriers to official

registration should be removed, funding or support to obtain funding for necessary accommodations should be increased, support should be provided to track consultation opportunities (e.g., through accessibility measures, reasonable accommodation, interpreter-guides/Deafblind interpreters, or through other OPDs), and technical support to improve organisational functioning should be increased. In some countries, OPDs of persons with deafblindness may experience communication barriers, restricting communication within the organisation. Therefore, rehabilitation services may be required. In addition, people with deafblindness who serve as proxies (i.e., in a representational capacity) should be confirmed by persons with deafblindness before representing this group.

Recreation and Participation in Social Life

Social life is essential for well-being and the capacity to thrive. of However, for persons with deafblindness, social isolation is a common challenge. Communication barriers reduce social interactions and can lead to very limited social circles of families and disability professionals. The key measures to tackle isolation and ensure social inclusion are access to interpreter-guide/Deafblind interpreter services, rehabilitation services that address barriers to social interaction, accessible information on recreational and cultural activities, accessibility standards and guidance for public recreational operators (e.g., venues, transport, etc.), support to OPDs of persons with deafblindness to arrange or enhance social opportunities (including peer or mentor networks), and sensitisation training for caregivers. Social activities need to be authentic, should be led by persons with deafblindness, and involve patience and plenty of time to ensure a smooth experience.

Preventing and Responding to Violence, Abuse, and Exploitation

Persons with deafblindness have increased risk factors for violence due to communication barriers (especially for those that have not developed comprehensive communication skills), access to information, caretaker dependency, and exclusion from protection programmes. However, there is little research on the topic of this group. To understand the prevalence, nature, and programmatic interventions for preventing violence against persons with deafblindness, more targeted research is required. Underreporting incidents of violence should not be interpreted as a lowincidence of violence. Interventions for preventing and responding to violence should include support for families to address the risks of violence across a variety of settings (e.g., in the home, school, care facilities, and the community); guidance and training for social workers, schools, interpreter-guides/Deafblind interpreters, and health centres on recognising the risks and patterns; accessible information on how to report violence (e.g., in sexual and reproductive health programmes); access to services specific for persons with deafblindness (e.g., interpreter-guides/Deafblind interpreters, assistive devices and technologies, etc.); and training for professionals in the justice system (e.g., police, judges, lawyers, etc.) to facilitate access to justice.

Response to Emergencies

Persons with disabilities are more likely to be left behind or abandoned during emergencies, such as disasters or conflict. There is emerging evidence of the experiences and interventions of persons with deafblindness arising from the COVID-

19 pandemic to inform wider emergencies. Some common good practices include the adoption of reasonable accommodations (specifically, sustained access to interpreter-guides/Deafblind interpreters) to access information and react to changing situations; information in accessible formats; accessible transport, distribution sites, and facilities; targeted community outreach and identification as a high-risk group; maintaining access to essential services; adaptable public guidance from authorities to ensure blanket guidance to the public does not exclude persons with deafblindness; guidance and training for frontline staff; safeguarding measures; identification cards with basic information on communication methods; and participation of OPDs of persons with deafblindness in emergency response planning. Implementing these procedures may help to establish protocols for communicating with persons with deafblindness in emergencies. In addition, those with deafblindness should be included in recovery programmes that seek to address the longer-term impacts of emergencies.

Conclusions and Recommendations

Building on the first global report, WFDB has expanded its quantitative analysis of the situation of persons with deafblindness, focusing on children, and set out detailed guidance on the good practices to improve the inclusion of all persons with deafblindness and to advance the implementation of the CRPD. Misperceptions and stigma about the capabilities of persons with deafblindness in combination with a lack of technical understanding of what works for persons with deafblindness are at the heart of their exclusion. Decision-makers in governments, NGOs, funders, OPDs, and other development stakeholders must develop a firm grasp of the concrete measures and interventions that work for persons with deafblindness based on this report, and each chapter can be used to assess and advocate for changes on specific policy areas.

This involves a systematic review of the preconditions for disability inclusion to ensure mainstream services are inclusive of persons with deafblindness, recognizing the overlapping nature of the preconditions. The report demonstrates many good practices in diverse settings, which often start out as pilot programmes. However, these small and often restricted programmes need to be replicated in other countries and scaled up. In addition, interventions that work for persons with deafblindness need to be included in more general disability-focused interventions to ensure that persons with deafblindness are not left out of potential advancements. Moreover, interventions that do not align with the CRPD, such as segregated education, segregated employment, or segregated residential services, continue to be a major concern, as these outdated practices need to be replaced with CRPD-compliant services and approaches.

The report provides targeted recommendations across 18 key policy areas, creating a roadmap for concrete change. The initial steps to bridge the gap and ensure persons with deafblindness are not left behind and include:

- 1. Recognition of deafblindness as a unique and distinct disability with its own challenges, barriers, and support and inclusion requirements
- 2. A system for information resources and continuous training on deafblindness in relevant languages for professionals in education, rehabilitation, health,

- social work, and other areas, to understand, identify, educate, and support persons with deafblindness
- 3. Publicly funded live assistance as an essential service, namely interpreterguides/Deafblind interpreters and teaching assistants
- 4. Funding for further research and data to support an evidence base of CRPD-compliant, disability-specific, and disability mainstreamed services with the active participation of persons with deafblindness and their OPDs.

This broad and diverse group requires reasonable accommodations for individuals, accessibility standards as a group, deafblindness-specific services, as well as mainstream services to ensure social inclusion, participation, independence, and autonomy.

This document is an executive summary of a full report. You can access the report in different formats and languages here.

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