# DISABILITY-INCLUSIVE DEVELOPMEN WITH MEN AND BOYS

Mainstreaming disability equality in approaches to engaging men and boys for gender equality









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# **Executive summary**

Official estimates of disability in the UNFPA Eastern Europe and Central Asia region range between 3 per cent and 6 per cent of the population, though these numbers likely underrepresent the true population of persons living with disabilities. There is growing evidence that disability increases one's vulnerability to all types of violence — physical, psychological and sexual. Traditional family values, which are common in many countries and embedded in social and political structures in the region, contribute to gender inequalities in the form of a gender pay gap and an unequal distribution of unpaid care work. In addition, women are engaged in informal work more frequently than men, and they are more vulnerable to trafficking and abuse. To address these persistent and systemic inequalities effectively, there is an urgent need not only to engage men as fathers, partners and allies in gender and disability equality but also to understand and address the unique needs of men and boys with disabilities.

As part of its efforts to ensure that approaches to engaging men and boys in gender justice are inclusive, the regional MenEngage platform for Eastern Europe and Central Asia, coordinated by the UNFPA Eastern Europe and Central Asia Regional Office and Country Offices in the region, commissioned research to better understand ways to mainstream disability equality in such approaches. Primary and secondary research was carried out to understand the global context for research at the intersection of men and disabilities, the Eastern Europe and Central Asian regional context, and current work being undertaken by UNFPA Country Offices.

This report is based on the following principles. First, all actors are urged to heed the "nothing about us without us" call from the disability equality movement. The best way to ensure this is to consult persons with disabilities and their representative organizations at all stages, taking into account the diversity of the disability community. Second, for work to engage men and boys in gender and social equality, including advancing disability equality for all, men should be seen as co-beneficiaries and as individuals with a vested stake in advancing gender equality rather than as the "problem". That is, while women and girls disproportionately suffer from gender inequality, harmful gender norms are bad for everyone. Men are negatively impacted by harmful gender norms and patriarchal systems, and most men actively oppose violence and care deeply about the women and girls in their lives. As such, rather than being cast as a problem getting in the way of equality, men should be seen as co-beneficiaries and stakeholders in the fight for gender and social equality and should be perceived as a necessary part of the solutions to achieving equality, justice, wholeness and full humanity for all.

# This report is based on the following principles

#### **Principle No. 1**

All actors are urged to heed the "nothing about us without us" call from the disability equality movement. The best way to ensure this is to consult persons with disabilities and their representative organizations at all stages, taking into account the diversity of the disability community.

#### **Principle No. 2**

Men should be seen as co-beneficiaries and as individuals with a vested stake in advancing gender equality rather than as the "problem". The report's findings and recommendations are broken down into the following categories



Men as

caregivers



Men as partners



Men and boys with disabilities - clients, service users and survivors



Men as allies and agents of positive change



The most abundant area of research identified, which is also frequently noted as a key area of interest and potential by UNFPA Country Office stakeholders, concerns fathers of children with disabilities. Evidence shows that supporting fathers of children with disabilities supports children and the broader family unit. However, fathers of children with disabilities need much more support than they are currently receiving, and social and cultural systems and norms need to change in order to facilitate more positive involvement on the part of fathers. As the broader field of fatherhood research tells us, early intervention is key for long-term positive impact, paternity/parental leave is an essential tool for engaging fathers early on and increasing the likelihood of their long-term contributions to care work, and other gender-responsive family-friendly workplace policies create an enabling environment for positive fatherhood and advancing gender and disability equality.



In terms of engaging men as partners and co-parents, research on parents of children with disabilities shows that positive father involvement decreases the stress levels of mothers (the research did not include same-sex couples) and improves mothers' well-being. This is in addition to creating opportunities for mothers to have more time and capacity to focus on their own career ambitions, thus further advancing gender equality.

Unfortunately, no research was identified on the role of men as partners of persons with disabilities. This is a key and urgent area where more research is needed, including regarding how supportive male partners of persons with disabilities impact their partner's well-being and health outcomes as well as how male partners of persons with disabilities could be engaged as allies in the movement to advance disability equality.



Regarding men and boys with disabilities, the research showed that men with disabilities are at higher risk of poorer health outcomes than men without disabilities, and they have considerable social and economic disadvantages as well, including lower levels of education and higher rates of unemployment than men without disabilities. Men with disabilities also appear to be at greater risk of having suicidal thoughts than men without disabilities. One of the few areas where one would expect more nuance and focus on the health needs of men with disabilities is the literature from the broader field of men's health. Unfortunately, the health needs and unique considerations of men with disabilities appear to be lacking in the already limited literature on men's health. The literature on the sexual and reproductive health needs of men and boys, another limited area of research, suggests that, whereas women and girls with disabilities tend to be perceived as asexual, the sexuality of men with disabilities is often pathologized and framed as a "problem to be dealt with". Researchers in this arena argue that men with disabilities, and in particular men with intellectual disabilities, need to be supported in more proactive ways, such as in developing healthy masculine sexuality, including learning how to have healthy and positive human connections with others.



Engaging men as allies and agents of positive change to advance disability equality can and should happen on many levels, but specific evidence of this work was not identified. Rather, and pulling from broader work to engage men and boys, public education and awareness-raising campaigns, including social norms campaigns and edutainment efforts, should highlight men in roles such as being a father of a child with disabilities, being a partner of a person with disabilities or being a man with a disability (beyond physical disabilities, in order to diversify representation).

Men in leadership positions, such as community leaders and those in political positions, should be engaged as allies. Men are also highly influenced by their social networks and in particular their own male peers, and efforts to engage men as allies should leverage men's relationships with other men so that men are doing the work of engaging and mobilizing more men. It is important to note that engaging men as allies of women and girls with disabilities should happen alongside conversations among men as well as in mixed-gender groups grounded in a gender-transformative framework that can help men (and women) understand the impacts of harmful gender norms so that men can become intrinsically motivated as co-beneficiaries of and stakeholders in gender and social equality, including disability-inclusive development.

Detailed recommendations for each area where men can be engaged to advance disability equality are included at the end of the document, followed by a disability-inclusive programming primer that includes political commitments and key underlying principles of work to advance disability equality, such as "nothing about us without us", which is provided in Appendix A.

In Appendix B, a life cycle–focused summary of the findings from this research in the form of a technical report (on masculinities and disabilities in the context of conflict and post-conflict settings) is provided to clarify key entry points for engaging men and boys throughout their lives.

It is important to emphasize that the research phase of the assignment was conducted before the full-scale invasion of Ukraine by the Russian Federation, in February 2022; as such, the issue of disability and masculinity in the context of this armed conflict and humanitarian emergency is only briefly covered at the end of the Recommendations (section 4). Given the substantial impact the war will have on gender dynamics, masculinity and disability, significant time and resources are needed to understand its specifics.

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# SECTION 1



1

Gender-transformative programming is crucial to ensuring gender justice and women's rights. Truly transforming social norms that drive gender inequality and injustice requires investment in gender-transformative programming and movements that engage and mobilize men and boys. The regional MenEngage platform for Eastern Europe and Central Asia, coordinated by the UNFPA Eastern Europe and Central Asia Regional Office and Country Offices in the region, is an alliance of civil society organizations (CSOs), governments, academia and UN agencies across 17 countries in the region. They work collectively and individually to generate and disseminate good practices on engaging men and boys for gender justice and healthy masculinity. The specific activities developed by the MenEngage platform members are rooted in UNFPA's mandate in the region, which includes developing gender-transformative programming, ending gender-based violence, ensuring sexual and reproductive health rights, and promoting youth and demographic resilience.

The global consensus to "leave no one behind" in implementing the 2030 Agenda for Sustainable Development and achieving the Sustainable Development Goals (SDGs) is the ultimate reason to make a targeted effort to ensure that the MenEngage platform includes persons with disabilities, who, according to global estimates, account for up to 15 per cent of the world's population. The movement for disability-inclusive development bodes well for the legal obligation to protect, promote and fulfil the rights of persons with disabilities that states have undertaken under the UN Convention on the Rights of Persons with Disabilities.

The recent adoption of the UNFPA Disability Inclusion Strategy, which will transform UNFPA's programming cycle and internal workings to ensure more effective disability mainstreaming, is the latest building block for guiding the MenEngage platform towards a more disability-inclusive approach.

### **1.1 Objectives**

The overall goal of this report is to support UNFPA and its partners in the Eastern Europe and Central Asia region in better mainstreaming disability in their work with men and boys to achieve gender justice and gender-transformative programming. The assignment called for the production of an analysis of issues underpinning disability and masculinities in the region and of specific suggestions to ensure a more disability-inclusive programme management cycle for MenEngage initiatives.

### 1.2 Methodology

The two lead consultants carried out primary and secondary research to understand the global context for research at the intersection of men and disabilities as well as the Eastern Europe and Central Asian regional context, in addition to current work being undertaken by UNFPA Country Offices. To begin, the authors held a UNFPA Eastern Europe and Central Asia regional consultative meeting (organized by the UNFPA Regional Office) that brought together UNFPA Country Offices working on engaging men or on supporting persons with disabilities (or both in some cases). The lead consultants then conducted one-on-one interviews with selected staff from UNFPA Country Offices. All Country Offices in the region were invited to provide documents they had produced on disabilities and masculinities or MenEngage, and the UNFPA Regional Office also provided additional documents and

resources for the consultants to review, which one of the consultants, a disabilities expert, synthesized as a brief overview. This regional and practitioner-focused research provided information on the work that is currently being carried out concerning persons with disabilities and/or engaging men for gender equality as well as how Country Office staff see this work, including potential tensions and cautions relating to working with men on issues of disability, given the disproportionate risks facing women and girls as well as their vulnerabilities. The research also explored gaps and potential areas where work could be initiated or integrated into existing efforts.

For the review of global literature on men and disabilities, one of the consultants, a masculinities expert, employed a systematic search strategy to identify relevant literature. The search involved two sets of terms: one covering terms relating to men and masculinities, the other covering terms relating to disability; these were reviewed by both the disabilities expert and the UNFPA team. The academic database used was EBSCO, including all its research databases, such as CINAHL and Academic Search Complete. An additional search was conducted in Google Scholar, and the results on the first three pages were reviewed; this search turned up only one additional publication. Within EBSCO, the initial testing of the search terms resulted in a surprisingly high number of articles matching the search terms, so the scope was reduced to include only those articles whose titles included the search terms.

# Literature, which could be published anywhere in the world, was included if it met the following criteria:

- It was a peer-reviewed article or grey literature.
- It was published in English or Russian.
- It was published between 2010 and 2021.
- The study focused on men and/or persons with disabilities, with at least 50 per cent of the target population/participants in the study being male.
- At least 10 men were included in the study sample, except for articles explicitly focused on the intersection of masculinity and disability and covering an identified area in which limited research had been conducted.
- Publications focusing on men with disabilities had to discuss masculinities as well.
- The content had to discuss intersections between masculinities and disabilities; the mainstreaming of disability in the context of engaging men, including global approaches and practices; and the benefits and drawbacks of engaging men as it relates to advancing disability equality.

Priority was given to systematic reviews and other literature reviews that synthesized literature, as well as publications on programmes that engage men regarding disability issues. In addition, publications based on populations in Eastern Europe and Central Asia were prioritized.

A search for terms within the titles of publications resulted in 939 hits. Following screening, the removal of duplicates and a full text analysis, a total of 44 publications were identified as matching the inclusion criteria. An extraction table was then developed to summarize key aspects of the relevant literature, which was used to inform the key findings.

# **1.3 Limitations**

The terms of reference for the consultants did not include field research. As such, no direct stakeholders (such as men and boys with disabilities, fathers of children with disabilities, male survivors of gender-specific violence, fathers with disabilities, etc.) were interviewed directly. This is an important limitation, given the global standard of "nothing about us without us" promoted by the international disability movement, whereby persons with disabilities should be involved directly and meaningfully in any initiatives that concern them. It is strongly recommended that the next phase — to plan, roll out, implement and evaluate disability-inclusive initiatives to engage men — include the direct participation of persons with disabilities and fathers of persons with disabilities.

In the same vein, the research methodology did not include interviews with a broad enough range of experts, such as civil society, academia, UN agencies, government representatives and other parties currently or potentially involved in or targeted by the MenEngage initiative. Only a small sample of experts could be involved directly in the research, which included one open webinar for the UNFPA Eastern Europe and Central Asia Regional Office and Country Offices, six one-hour bilateral interviews with staff from selected UNFPA Country Offices and a select number of informal interviews with the consultants' contacts to further inform this work. It is therefore highly likely that the nuances of other stakeholders' viewpoints on the disability-inclusive engagement of men may vary. These nuances should be reflected in the next phase of the process.

The limited resources allocated to the assignment did not allow for an in-depth analysis of the specificities of UNFPA programme cycle management and the programming tools that are already available for UNFPA staff. Indeed, only general recommendations for a disability-inclusive programme management cycle could be formulated at this stage. It is expected that the recently adopted UNFPA Disability Inclusion Strategy will inform future programming cycles and the place of disability mainstreaming in them. It is hoped that UNFPA's MenEngage platform will receive more concrete and practical guidance and support from the Disability Inclusion Strategy implementation tools. Furthermore, due to the humanitarian crisis currently unfolding in Ukraine, input from Country Offices was limited despite efforts to obtain feedback, and an additional consultative process to further specify which recommendations to prioritize would be very valuable.

It is important to emphasize that the research phase of the assignment was conducted before the full-scale invasion of Ukraine by the Russian Federation, in February 2022. While media reports show the devastating (yet not unpredictable) and disproportionate impact of the war on women, men and children with disabilities, the issue of disability and masculinity in the context of the armed conflict and humanitarian emergency is covered only briefly at the end of the Recommendations (section 4) and is based primarily on anecdotal information and a brief conversation with a UNFPA Ukraine Country Office staff member still residing in Ukraine. Since the fall-out and long-term consequences of the war are likely to have a substantial impact on how masculinities and disabilities are engaged with and addressed in the region, the allocation of significant time and resources is recommended to understand the specifics of this impact.

# SECTION 2 REGIONAL CONTEXT

ONFPA Belarus

# 2.1 Men, masculinities and gender norms

The effects of gender inequality are disproportionately damaging to women and girls. Rigid gender norms, however, wreak havoc on all members of society, including men. Men – and the boys who become them – are not born violent (Walker, 2020). Instead, they are born into the social and cultural waters that surround them, soaking up the gendered rules and expectations for behaviour and learning to connect with others – and themselves – from within this context. This inculcation of gender norms begins in infancy, and as a result boys quickly learn that their basic human instincts and needs for love and connection are strongly discouraged, and that they have to find other ways to express themselves.

In Eastern Europe and Central Asia, like in many other regions of the world, dominant notions of masculinity teach boys and men to exist within a prescribed "man box", where they are rewarded for physical toughness and risk-taking behaviour, expected to channel emotional expression into aggression and anger, celebrated for their sexual prowess and punished for anything perceived as weakness (e.g. expressing desires for love and connection, health-seeking behaviour). The man box demands that men function as self-sufficient and capable leaders, and yet attempting to fulfil the expectations of the man box is futile, leaving many men on an unending journey of increasingly destructive and violent behaviour. For example, high rates of unemployment are a reality in the region, which can be particularly devastating when one's sense of worth as a man is tied to one's ability to contribute financially (Dušanić, 2012; Hughson, 2018; UNDP, 2017; UNFPA, 2018b).

Although the majority of the victims of violence at the hands of men are women and girls, men also use violence against other men. For example, one of the three main causes of death among men in the region is interpersonal violence (World Health Organization Regional Office for Europe, 2018). And indeed, where rates of violence against women are high, so too are rates of interpersonal violence among men, including as victims of violence themselves (Jewkes, Flood and Lang, 2015). Importantly, the other two main causes of death – unintentional injuries (including traffic accidents) and suicide – speak to the self-inflicted harm caused by masculine norms that encourage extreme risk-taking behaviour, demand outward toughness, and equate vulnerability with weakness and shame.

In Eastern Europe and Central Asia, a region that has both long and recent experiences of armed conflict and war, harmful notions of masculinity are particularly prominent as men struggle under the weight of unspoken trauma and helplessness due to violence and economic uncertainty. Furthermore, fragile claims of male superiority under the guise of traditional family values have driven the male domination of the public sphere in the region, while this emphasis on traditional norms has also operated to disempower and limit options for women (Watson, 1993) while also fomenting homophobia in the region. At the same time, the presence of such hypermasculinity also helps illuminate the futility of remaining in the man box (Roberts, 2022), and as a result the region is also witnessing a growing movement of men who are refusing to internalize these gender norms and are redefining what it means to be a man within a more gender-equitable future.

Still, gender-inequitable attitudes remain pervasive in the region, particularly among men, although there have been notable progressive shifts among younger generations. The following paragraphs rely on the findings of the International Men and Gender Equality

Survey (IMAGES), which has been carried out in nearly 30 countries globally, including in Azerbaijan, Bosnia and Herzegovina, the Republic of Moldova, Serbia and Ukraine. In Azerbaijan, for example, women still do the majority of care work, but over half of men report believing that men should share household tasks, and feel that they would like to contribute as fathers in more ways than just financially (UNFPA, 2018a). The majority of men and women in countries such as the Republic of Moldova and Bosnia and Herzegovina believe that the most important role for women is to take care of domestic duties, including giving up their career to do so, while men are expected to be the breadwinners (Cheianu-Andrei and others, 2015; Dušanić, 2012; UNFPA, 2018b). Permissive attitudes towards violence against women are also common in the region; for instance, over 40 per cent of Moldovan men believe that beating a woman may be justified (Cheianu-Andrei and others, 2015).

It remains incredibly rare for men in Serbia to attend the birth of their children, with only 2.4 per cent of men in the IMAGES study reporting having done so; further, only 1 in every 50 men takes parental leave (Hughson, 2018). However, in Ukraine 13 per cent of men interviewed in 2018 said that they had attended the birth of their last child (UNFPA, 2018b), and men attending their child's birth is on the rise in the Republic of Moldova, with researchers noting that cultural norms and structural barriers contribute to men's absence at their child's birth (Cheianu-Andrei and others, 2015). IMAGES findings from both Serbia and Bosnia and Herzegovina show that, while the majority of fathers living with their children play with their children, significantly fewer men feed, dress or bathe their children (Dušanić, 2012; Hughson, 2018). Particularly for those under 30, however, decision-making in couples is increasingly looking more equitable, with three quarters of men and women in the Serbia IMAGES study reporting a more egalitarian division of labour and decision-making, including about matters such as children (Hughson, 2018). In addition, numerous studies in the region found that men would like to spend more time with their children (UNFPA and Promundo, 2018; UNFPA, 2018b; Hughson, 2018; OSCE and UNFPA Kosovo, 2018).

#### **Country in context: Serbia**



of men in Serbia attended the birth of their children



While the majority of fathers living with their children play with their children, significantly fewer men feed, dress or bathe their children



#### DECISION-MAKING IN COUPLES IS INCREASINGLY LOOKING MORE EQUITABLE

Three quarters of men and women, particularly those under 30, report a more egalitarian division of labour and decision-making, including about matters such as children

It is encouraging that half of men in the Bosnia and Herzegovina IMAGES study supported the "existence of quotas which guarantee the share of women in power, education and managerial positions" (Dušanić, 2012, p. 9). However, over half of men and women in numerous regional IMAGES studies perceived gender equality as only benefiting those in better socioeconomic standing, and not improving the lives or conditions of vulnerable people (Kachkachishvili and Nadaraia, 2014; Osipov and Sargizova, 2016; UNFPA, 2018a). Furthermore, numerous IMAGES studies in the region found that a significant portion of men, and to a lesser extent women, believed that women's empowerment and the increase in women's rights resulted in a loss of men's rights (UNFPA, 2018a; Cheianu-Andrei and others, 2015; Osipov and Sargizova, 2016). This speaks to the necessity of raising awareness of the fact that men are co-beneficiaries of efforts to advance gender equality and making it clear that everyone has a vested interest in breaking free from rigid gender norms and living as whole, nurturing and nurtured humans. It also highlights the need to better integrate social justice and social equality efforts – for example, it is essential to better understand the needs and realities of persons with disabilities in work to engage men to advance gender equality.

# 2.2 Disability in the region

Around 135 million people in Europe and Central Asia are living with a disability (WHO, 2022), with national rates ranging from 3.3 per cent in Georgia (2014) and 3.7 per cent in Kazakhstan (2019) to 5.9 per cent in Ukraine (2021) and 6 per cent in Belarus (2018), according to periodic reports presented by States Parties to the UN Convention on the Rights of Persons with Disabilities.

Quantitative data from UNFPA research supports the global evidence that the prevalence of disability in men increases with age and is often due to external factors that could be eliminated, such as accidents, workplace injuries, violence and substance abuse (UNFPA, 2018b). Men with disabilities have been found to have a significantly lower level of education than men without disabilities (25 per cent and 9.3 per cent, respectively) and are more often unemployed (UNFPA, 2018a).

The outdated system for determining disability, firmly based on the medical model of disability, and archaic data collection systems are the dominant reason behind the alarmingly low official numbers of persons with disabilities in the region. With minor national differences, the disability determination system is usually diagnosis-based and evaluates a person's ability to work with little regard for societal barriers and the limited availability of individualized rehabilitation, support or assistance. People who are classified as "unfit to work" are eligible for disability pensions; others are subject to a range of often controversial and disincentivizing "privileges", such as a longer leave period, a prohibition from working weekends or the right to full-time pay for part-time work. In some countries (UNFPA, 2021b; stakeholder interviews), disability statistics are not disaggregated by gender, making the design and provision of gender-sensitive services a challenge.

#### Disability stigma as a factor preventing self-identification

The stigmatization of disability combined with the application-based approach to disability determination serve as a significant deterrent to participation in an assessment for persons with disabilities. Societal prejudice, discrimination and fear of the "disability" label discourage many people, especially those with psychosocial disabilities, from self-identifying as having a disability and undergoing a disability assessment that is often an administratively complex, expensive and stigmatizing procedure in itself.



"Participation in dads' clubs involves filling out a questionnaire that includes a question on self-identification as a person with a disability. Many men leave it blank because they don't know how to answer this question or don't want to disclose the information. So we don't actually know how many participants with disabilities we have in clubs." – Interview with a staff member from a UNFPA Country Office

Children with disabilities are one of the most vulnerable cohorts in any society due to the lack of a supportive environment and of accessible and inclusive services, such as education, care, rehabilitation and social support. In many communities, raising a child with a disability is a stigmatizing and lonely experience for the parents or carers due to societal prejudice, fear and ignorance. Women are generally expected to be the primary caregivers for all children, and particularly for children with disabilities, while it is not uncommon for men to leave their families once they learn their child has a disability. Fathers wishing to take on more family responsibilities are sometimes actively discouraged from doing so, as it is perceived as "unmanly".

Fathers of children with disabilities are often expected to leave their families and start anew. Those who stay in the family are celebrated and hailed as heroes by their communities. Mothers, however, are always expected to stay and "atone for their sin" of giving birth to a disabled child by raising them.

 A staff member from a UNFPA Country Office

The medical model of disability pervasive in the region is the core factor behind the inequality and discrimination experienced by children with disabilities and their families: a child with a disability is considered "broken" or "abnormal". Most available resources are thrown at attempts to "fix" the child, sometimes with unnecessary interventions that are not based in science. This happens at the expense of early identification, intervention and referral, and the development of personalized support services in the community.

Although the rate of institutionalization is generally on a (slow) decline in most countries in the region, organizations for parents of children with disabilities throughout the region report that new mothers of children with disabilities encounter prejudice, and that they are routinely advised to abandon their children with disabilities to state care. When her child was born, the doctor quickly told her it was Down Syndrome. He recommended giving up the child and offered to tell her husband that the child was stillborn. The doctors painted a very black picture, said the child would be a vegetable, prone to aggression, using very rude words to describe her baby. They tried to make her afraid of her own child. They were very quick and efficient to give her instructions on the procedure to give up her child, but no information about available support. She was so ashamed she left the maternity ward via the side entrance.

She came to an orphanage in [the capital city] to place the child into care. There was no counselling, no asking her about the reasons. It was by chance that she met a nurse who said something nice about the baby and gave her alternative information about Down Syndrome. She came to our support centre with a 10-day-old baby and received counselling, support and services. She changed her mind and her now school-age child lives with her at home.

- Representative of a support and learning centre for children with disabilities (reprinted with permission from UNICEF Uzbekistan, 2021)

The experience of disability activists in the region shows that mothers are targeted with information about their child's disability and the expected outcomes in terms of their health and quality of life. The information is often negative, outlining the health challenges their child is expected to experience and the impact the child is likely to have on their family's well-being. This also means that fathers are assumed to be uninterested, further hampering the likelihood that they will take an active role in understanding the needs of and caring for their child.

# 2.3 Sociodemographic trends in the region

No discussion about the opportunities for and challenges of disability-inclusive engagement of men in the region would be complete without a sociodemographic analysis that informs the regional trends in the field. Eastern Europe has experienced decreases in fertility rates coupled with ageing populations, leading to net population decreases in all countries and territories in the region. On the other hand, Central Asia and Türkiye still have relatively young populations, with above-replacement fertility rates, leading to net population increases (United Nations, Department of Economic and Social Affairs, Population Division, 2023). However, this is set against the backdrop of an increasingly ageing population in which both women and men are experiencing extended lifespans, but men are still more likely to die prematurely, leaving their female counterparts at increased risk of facing poverty in their old age as they outlive men (by an average of 6.1 years) and in a context of social and structural gender inequalities (Fillo and Negruta, 2020). Taken together, these factors have sparked a reflection on the role of families in society and the supports needed to help families thrive.

In recent years, the region has experienced significant destabilization due to internal and cross-border armed conflicts that have resulted in an increased number of war veterans (most of them men, some with disabilities) and large numbers of internally displaced persons and refugees. The recent and devastating full-scale invasion of Ukraine by the Russian Federation will further exacerbate this destabilization and increase the number of war veterans.

The traditional family values prevalent in many countries in the region contribute to gender inequalities in the form of a gender pay gap, the unequal distribution of unpaid care work, the greater likelihood that women will engage in informal work, and vulnerability to trafficking and abuse. Anecdotal evidence suggests that women and girls with disabilities bear the brunt of discrimination in two ways: they are deprived of equitable access to resources, including food, care and education, on account of their gender and their disability, and they are disproportionately affected by violence and exploitation and experience a range of human rights violations, including forced impregnation, sterilization and abortion, removal of their children, modern-day slavery and physical deprivations. They are also more likely than their male peers to hold negative stereotypes about their own disabilities and perpetuate self-stigmatization (UNFPA, 2020).

# 2.4 Gender-based violence

There is growing evidence that disability is a factor that increases one's vulnerability to all types of violence, including physical, psychological and sexual violence (Dammeyer and Chapman, 2018). Experiencing violence in childhood – regardless of disability status – is often a factor that contributes to experiences of violence in adulthood, and violence tends to be passed down from one generation to another (WHO, 2022). Men in the region are more likely to have witnessed intimate partner violence as children than their female counterparts, and men are more likely to be exposed to violence (Hughson, 2018; UNFPA, 2018a). It is important to emphasize that the opposite is true as well – for example, the IMAGES study in Azerbaijan confirmed that men who witnessed their own fathers contributing to caregiving and domestic duties were more likely to be gender-equitable and nonviolent men themselves (UNFPA, 2018a).

Men and women who experience violence as children are more likely to adopt harsh approaches to discipline with their own children, and boys are more likely to experience bullying, physical violence and violent discipline as children, particularly in schools (UNICEF, 2015; UNFPA and UNICEF, 2018). Men in Azerbaijan reported experiencing "more severe forms of physical violence as children, with six times more men than women reporting childhood beatings with hard objects" (UNFPA, 2018a). In Moldova, nearly 40 per cent of men reported experiencing an atmosphere of intimidation, either always or sometimes, in their educational institutions in childhood (Cheianu-Andrei and others, 2015). Additionally, boys who have adverse childhood experiences are more likely to grow up and perpetuate violence against their intimate partners (UNFPA and UNICEF, 2018). This fact suggests that preventing experiences of violence in childhood can have long-term benefits. Men in the military also reported that they had frequently experienced abusive or violent treatment at the hands of officers (UNFPA, 2018b). Research shows that men with disabilities are more often subjected to physical violence than women are, while women and girls with disabilities more often report sexual violence, harassment and discrimination.<sup>1</sup>

People with intellectual disabilities are particularly vulnerable to all types of violence due to communication barriers, and they often rely on third parties to complete daily tasks

<sup>1.</sup> United Nations, Department of Economic and Social Affairs, "Women and girls with disabilities". Available at <a href="https://www.un.org/development/desa/disabilities/issues/women-and-girls-with-disabilities.html">https://www.un.org/development/desa/disabilities/issues/women-and-girls-with-disabilities.html</a> (accessed on 18 March 2023).

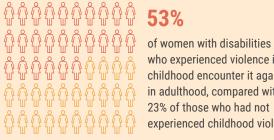
(Dammeyer and Chapman, 2018). Fifty-three per cent of women with disabilities who experienced violence in childhood encounter it again in adulthood, compared with 23 per cent of those who had not experienced childhood violence (UNFPA, 2020). Over a quarter of women with disabilities (26.6 per cent) reported that they had experienced physical, sexual or psychological violence during their childhood, which is higher than among women without disabilities (20.3 per cent). The perpetrators of violence against children with disabilities are usually the child's parents (56.6 per cent); for women with disabilities, the perpetrators are most often their intimate partners (UNFPA, 2020). Research indicates that high-risk partners of women with disabilities share certain characteristics - for example, they are typically aged 35-39, out of work, have secondary education (as opposed to either primary or tertiary) and frequently consume alcohol (UNFPA, 2020). Additional factors that increase one's vulnerability to violence are having children, living in poverty, living in a rural area or being a refugee.

#### Violence against girls and women with disabilities

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of women with disabilities reported that they had experienced physical, sexual or psychological violence during their childhood, which is higher than among women without disabilities (20.3%)



who experienced violence in childhood encounter it again in adulthood, compared with 23% of those who had not experienced childhood violence

HIGH-RISK PARTNERS OF WOMEN WITH DISABILITIES SHARE CERTAIN CHARACTERISTICS For example, they are typically aged 35–39, out of work, have secondary education (as opposed to either primary or tertiary) and frequently consume alcohol

It is important to emphasize that, while women and girls are much more likely to experience sexual violence, men and boys are also victims of sexual violence, often at a much higher rate than anticipated, and because of constricting masculine norms they are much less likely to report or seek help or treatment (Taylor and others, 2021; World Health Organization Regional Office for Europe, 2018). Because of these norms and societal reticence to see men as victims, research is limited on the prevalence and experiences of sexual violence among men. However, a 2011 meta-analysis of child sexual abuse estimated that from 4 per cent to 32 per cent of boys are victims of child sexual abuse (Stoltenborgh and others, 2011). Sexual violence against men and boys during war and other forms of armed conflict is also often hidden and severely underreported. For example, the Bosnia and Herzegovina UNFPA Country Office reported that an estimated 20,000 women and 5,000 men experienced wartime rape, noting that suicide rates among this population were particularly high (United Nations, Special Rapporteur on violence against women, its causes and consequences, 2013). A UNFPA report based on the experiences of 109 refugee men who were survivors of sexual violence in the region found that 17 per cent of them were living with disabilities, with the majority of them having become disabled as a result of the sexual violence they experienced (UNFPA, 2022).

# 2.5 Advocacy and civil society activism in the region

The development of civil society in the region is not uniform: while civil society in some countries is evolving in a dynamic and systematic manner, in other countries factors such as political and economic instability, corruption, and lack of access to resources and information result in a more restricted civic space for activists.

Disability activism takes place in all countries in the region in different forms. Stemming from the historical emphasis on fitness to work as the key determiner of one's degree of disability in the Soviet Union and other countries sharing a socialist past, the oldest and most-established disability organizations have traditionally focused on various aspects of employment and social protection. These have typically been impairment-specific membership organizations, representing people who are blind or visually impaired, people who are deaf or hearing-impaired, or those with mobility disabilities. Many of these organizations have been the main employer of people with specific impairments (for example, many national organizations for the deaf and for the blind run production and service provision enterprises that employ their members and provide in-kind assistance, support and leisure activities). With few exceptions, these organizations have been led and continue to be governed by men with or without disabilities.

The emergence of new types of disability organizations — including for women with disabilities and for young people with disabilities, organizations that bring together parents of children with disabilities as well as those representing people with intellectual disabilities, chronic diseases and other impairments — is a fairly recent development in the region, which was encouraged by the adoption, in 2006, of the UN Convention on the Rights of Persons with Disabilities and its gradual ratification by all but one country in the region.

#### **Central Asian Network of Women with Disabilities**

The <u>Central Asian Network of Women with Disabilities</u> is a regional project conducted by organizations of women with disabilities in Kazakhstan (<u>Shyrak</u>), Kyrgyzstan (<u>Ravenstvo</u>) and Tajikistan (<u>Ishtirok</u>). Established with financial support from Kynnys (Finland), the network has three key objectives:

- 1. to raise awareness of gender and disability and to help women and girls with disabilities in Central Asia exercise their rights
- 2. to build the capacity of members of the network
- 3. to fight against prejudice against women with disabilities in Central Asia

The network addresses issues such as the sexual and reproductive rights of women and girls with disabilities, violence against women with disabilities, education, livelihood and mobility. It relies on cross-border information exchanges and peer support as key tools to empower girls and women with disabilities in the region.

Although limited research has been conducted on the dynamics of the regional movement of persons with disabilities, the empirical evidence suggests a certain dissonance between the different types of disability organizations active in the region in terms of their agendas and working methods.

Although caution must be exercised when generalizing, it is often observed that, while traditional umbrella and disability-specific organizations work on the broadest range of issues under the Convention on the Rights of Persons with Disabilities, they are vocal predominantly on issues of accessibility, employment and social protection. As a result, issues that are specific to women and marginalized groups of persons with disabilities, such as reproductive rights, deinstitutionalization or protection against violence (including sexual violence) sometimes do not get the attention they deserve. While the structure of organizations representing persons with disabilities will vary, it has been noticed that few of them mainstream women's issues in a systematic way by, for example, including women on their boards, setting up women's committees or specifically including gender issues in their strategic relations with the government.

Organizations for parents of children with disabilities are often lauded for being particularly proactive and vocal in their activities. They usually have true grass-roots origins, with parents' chapters present in most regions, and — in the absence of sufficient government support — they undertake a range of innovative experiments in addition to advocacy work, such as peer support groups, early intervention services, support in education, as well as counselling and respite care for parents and carers. In striking contrast to large disability organizations, parents' associations are usually governed and animated by women — mothers of children with disabilities — who are at the forefront of advocacy activities and service provision, as well as key beneficiaries of support, alongside children with disabilities.

Lately, we've had more and more new dads of children with Down Syndrome making the initial contact with our Centre, asking for information about raising a child with a disability. But when it comes to daily work with the child, bringing the child to lessons and therapies, it's all on the woman's shoulders. We don't have any dads' clubs, no one's even thought about it because it's considered by default that the mother is responsible for children's upbringing. Even when dads want to participate, it's not always possible, such is the culture.

- Director of an educational centre for children with intellectual disabilities, leader of a grass-roots peer support network for families of children with Down Syndrome

# SECTION 3 KEY FINDINGS

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This section provides the key findings from the research conducted for this project. The findings include input from UNFPA Country Offices and the documents they provided as well as the results of a global literature review. The first section discusses the theoretical frameworks identified for thinking about the intersection of masculinities and fatherhood research with disability studies. The subsequent sections (3.2 to 3.5) break down the findings within an adapted version of the framework for the involvement of men in reproductive health — men as clients, partners and agents of positive change — developed by Margaret Greene and others (2006). The authors adapted this framework in response to the literature reviewed on men and disabilities to cover the following categories:



### 3.1 Theoretical frameworks for men and disabilities

The intersection of masculinities and disability has been a growing area of inquiry since the late 20th and early 21st centuries. According to Shuttleworth, Wedgwood and Wilson (2012), much of the literature that looks at "disabled masculinity" has focused on men with *physical* disabilities and in particular men who acquired their disability at some point in childhood or adulthood. This literature argues that "masculinity and disability are in conflict with each other because disability is associated with being dependent and helpless whereas masculinity is associated with being powerful and autonomous, thus creating a lived and embodied dilemma for disabled men" (Shuttleworth, Wedgwood and Wilson, 2012, p. 174). Early scholars in this area, such as Hahn (1989) and Asch and Fine (1988), argued that, as a result of this so-called inherent conflict between "being a man" and "being disabled", men with disabilities often attempt to compensate for their conflictual reality by either overemphasizing other aspects of masculinity (i.e. challenging the notion that disability is weakness and that, instead, it is another example of strength).

Gerschick and Miller's typology of masculinity and disability (1995), which was grounded within Connell's theory of masculinities (1995), adds to these theoretical underpinnings but again focuses on men with physical disabilities. Derived from interviews with 10 disabled men, Gerschick and Miller contended that men with a disability adopt one of three strategies as a means of "coming to terms" with masculinity and disability as normatively defined. "The first strategy, reliance, involves a continued adherence to conventional configurations of masculinity. The second strategy, rejection, is characterised by the renunciation of idealised notions of masculinity and potentially the denial of the importance of masculinity to one's identity. The final strategy, that of reformulation, entails adopting a

mode of masculinity which involves a tactical recalibration of hegemonic masculinity that is consistent with a man's resources and capacities" (Pini and Conway, 2017, p. 267).

A key turning point in the study of disabled masculinity, Gershick and Miller's typology led them to argue that, although these responses were by no means mutually exclusive, "men who reformulated masculine ideals, although distancing themselves from hegemonic masculinity, did not present a challenge to the gender order because they still perceived their dilemma as an individual project" and that "rejection offered the most hope for change which they linked to a socio-political model of disability" (Shuttleworth, Wedgwood and Wilson, 2012, p. 177).

It is imperative to note that Shuttleworth, Wedgwood and Wilson (2012) caution that the majority of the perspectives informing these theories about disabled masculinity are based on men with physical, and specifically spinal cord, injuries, and that such injuries represent only a tiny slice of the overall experiences, perspectives and realities of men with disabilities. Shuttleworth, Wedgwood and Wilson (2012) thus urgently call for more research on how masculinity interacts with other types of impairment and disabilities. It is important to note that the cited article was published in 2012, and apart from Shuttleworth and Wilson's additional publications described below, no other more recent work that responds to this call was found through the literature review.

Wilson and others (2011) argue that men and boys with moderate to profound intellectual disabilities experience what the authors term "conditionally sexual", a "theoretical notion" that they define as follows:

A life that is reduced to a penis/body-centric experience. Furthermore, the focus on these men and teenage boys' masculine sexuality is not geared toward what is developmentally normative, what feels nice and what is fun. Instead, their sexuality is problem-led within a service-centric risk-hierarchy that renders to a secondary consideration the "right" to develop a healthy masculine sexuality. Their lives, and their masculine sexualities, are circumscribed by an environment whose prime purpose is led by their day-to-day high "physical" support needs at the expense of supporting an individual within a broader socio-cultural "sexually healthy" framework. Their "personhood", as espoused by documents such as the UN Declaration [on the Rights of Disabled Persons], is denied because of cognitive limitations and policy shortcomings. (Wilson and others, 2011, p. 286)

In Wilson and others' (2012) piece focusing on applying masculinity theory in research with men and boys with intellectual disabilities, the authors aim to "consider what mainstream theories of masculinity may offer to applied research on, and hence to therapeutic interventions with, men and boys with intellectual disability" (p. 261). They offer five areas within the disability (and in particular intellectual disability) and masculinity fields that they argue are currently under-researched and call for the application of theories of masculinity in their research. They are as follows:

- 1. fathering, in particular the experiences and lives of fathers of children with intellectual disabilities
- 2. male physical expression, such as examining why men with intellectual disabilities tend to be more physical in their expression than women with intellectual disabilities

and seeing how to shift the conversation from considering male physical expression problematic to focusing on health and well-being, including research on whether more engagement in sport and other physical activity might reduce the incidence of these behaviours

- 3. sexual expression, specifically moving away from pathologizing male sexuality among those with disabilities to being more proactive and focusing on health and well-being
- 4. men's health, noting that there is a need for more specific health guidelines for men with intellectual disabilities
- 5. underweight and obesity, noting that a higher percentage of women than men with intellectual disabilities are considered obese, and men with intellectual disabilities are more likely to be underweight than their female counterparts (as such, more research should be done that looks at the interplay between body mass and gender roles in men and women with intellectual disabilities)

In terms of theoretical underpinnings for fathering children with disabilities, offerings in this area are even more sparse. Despite two recently published literature reviews - one a systematic review on fathers of children with intellectual disabilities (Langley, Totsika and Hastings, 2020) and the other a scoping review on fathers of children with developmental disabilities (Boyd, Iacono and McDonald, 2019) - neither of them provides specific theoretical frameworks for their reviews, beyond noting that the majority of research on parenting children with disabilities has focused on mothers. The only publication that does provide a theoretical framework is Mitchell and Lashewicz's (2019) piece on generative fathering, which was informed by Erikson's (1950) theory of psychosocial development; this framework is "used by researchers and professionals to conceptualize fathers' parenting capacities and strengths" (Mitchell and Lashewicz, 2019, p. 185). The generative-fathering framework works across the lifespan of children and across multiple categories, including relational, spiritual and recreational. Explicitly interfacing the generative-fatherhood framework with critical disability studies, the authors aimed to "[enrich] understandings of fathering children with disability diagnoses" (Mitchell and Lashewicz, 2019, p. 185). They argue that a disability-informed generative-fathering framework highlights (1) varieties of stewardship fatherwork as fathers balance providing for, and equipping, their children; (2) dynamics of reciprocal connection characterizing generative labour embedded in the apparent fun and games of recreational activities; and (3) fathering growth amid challenges as fathers discover and use less conventional development fatherwork in supporting their children (Mitchell and Lashewicz, 2019, p. 194).

Through their work, Mitchell and Lashewicz help to illuminate the ways that fathers of children with disabilities are both pushed towards many traditional gender norms (e.g. expectations to be financially dependable given the additional financial realities that so often go with having children with disabilities; assumptions of not being their child's primary caregiver, as women, particularly in the Eastern Europe and Central Asia region are much more likely to be primary caretakers of children with disabilities), but as a result fathers of children with disabilities also have a unique opportunity to redefine their relationship to their gender identity and fatherhood given the intense and unique demands of raising a child with a disability.

# 3.2 Men as fathers: men as parents and caregivers

#### A note on language

Recognizing that the term "father" can sometimes be exclusionary to a variety of maleidentified caregivers, we define "father" broadly to include male-identified individuals who function as a child's caregiver. This includes biological fathers as well as "adoptive fathers, foster fathers, stepfathers, father figures, transgender fathers, and relatives or friends who serve as father or male identified surrogates" (Dozois and others, 2016, p. 6). However, it is important to note that much of the research on parenthood, whether within the disabilities literature or otherwise, tends to lean on traditional notions of gender and motherhood and fatherhood. As such, we use more inclusive language here where possible but refer to "mothers" and "fathers" where it is necessary to stay true to research findings.

#### **Positive fatherhood**

One of the most promising – and most needed – entry points to engage men for violence prevention and gender equality is fatherhood. For one, women globally spend substantially more of their time in unpaid (and paid) caregiving roles, which leads to notable gender disparities in a variety of ways (van der Gaag and others, 2019). As noted in Promundo's *State of the World's Fathers* report, "Change in terms of who does the daily care work in our homes is needed, and urgently, if we want a significant shift in power relations between women and men and to bring about gender equality" (van der Gaag and others, 2019, p. 8).

Programmes and initiatives that promote "positive fatherhood" can be defined as those that encourage fathers to promote "their child's well-being and security by taking an active role in caring for their child's social, emotional, cognitive and physical health, and by having a respectful, equitable relationship with the child's mother or co-parent" (Pascoe and others, 2022, p. 24). Fathers play a distinct and unique role in their children's lives, and positive fatherhood for all children, particularly those with disabilities, results in improved social, emotional, cognitive and health outcomes for children, and also holds great benefit for mothers (or co-parents) and fathers themselves (Hansen, Pascoe and Wells, 2022). There is substantial and clear evidence that positive fatherhood is not only a key primary prevention strategy; it also produces measurable and positive outcomes for men, their partners and their children (Hansen, Pascoe and Wells, 2022). As Promundo notes,

Greater involvement by men in daily care work brings benefits for everyone. Having involved fathers is good for gender equality. It is good for women's health. It leads to better relationships within couples and can be linked with a reduction in rates of men's violence against women. It is good for children, too. There is ample evidence from all over the world that engaged fatherhood has a positive impact on boys and girls – and the relationships they will have as adults. Girls are more empowered, and boys are more likely to believe in gender equality and to share the unpaid work if they saw their fathers do the same. (van der Gaag and others, 2019, p. 9)

Supporting fathers of children with disabilities supports children and the broader family unit. However, fathers of children with disabilities need much more support than they are currently receiving, and social and cultural systems and norms need to change in order to facilitate greater positive involvement on the part of fathers. For this project, the literature review included 28 articles on issues relating to fathers of children with disabilities, with three of these articles being global reviews of the evidence (thus, some of the individual articles identified likely overlap with some of the publications included in these global reviews). Articles on fathers of children with disabilities covered issues such as quality of life, coping strategies and the mental health of fathers of children with disabilities, strategies to engage fathers, unique experiences, etc. It is important to note that an issue with much of the research on fathers of children with disabilities is that it often includes only couples for purposes of controlling variables. As such, single parents or divorced parents are not included, which makes understanding those nuances challenging.

However, UNFPA is already conducting promising work in the Eastern Europe and Central Asia region to engage men through fatherhood, including the following:

- fathers' clubs (also known as dad hubs), with current work and goals set for ensuring the inclusion of fathers of children with disabilities (multiple countries)
- » a book and programme on responsible fatherhood and responsible husbands, including a focus on positive trends in these areas and also on single fathers (Kazakhstan)
- » paternity leave (multiple countries)
- » engagement with men in antenatal care (Georgia)

There is also recognition of the need to address harmful notions of masculinity that often drive men to back out of their parenting responsibilities in the region. One respondent -a staff member from a UNFPA Country Office - said the following:

Men have no social cost [from abandoning] their families, but [for] women the social cost is huge ... But the same man who would abandon their child with disabilities is the same one who would kick out their kid if they were gay. We need to start examining the root causes of these issues, looking at what it means to be a woman and what it means to be a man, including breaking down toxic masculinities and promoting new notions of masculinities.

One of the most striking findings of the research is that fathers of children with disabilities may face increased pressure to conform to traditional male gender roles, such as prioritizing work in order to earn sufficient income to cover the additional costs of raising a child with a disability. In a study using Australian survey data from 420 families to examine "whether caring for children and young people with disabilities affects paid employment participation of fathers who identify as the secondary caregiver" (Wright, Crettenden and Skinner, 2016, p. 341), the researchers found that over a third of fathers reported that "caring had impacted on their job opportunities or career progression, particularly those whose children had more severe disabilities" (Wright, Crettenden and Skinner, 2016, p. 341). Further, "the financial costs of raising a child with disabilities and their caring obligations informed many of the decisions fathers made in relation to employment.

"Fixed hours of work, lack of understanding from their employer, an income tied to hours worked and staff resources were cited as reasons why almost half of the fathers felt they were unable to access flexible working conditions to assist with their child's care" (Wright, Crettenden and Skinner, 2016, p. 341).

The authors point out that "the issues raised by these fathers – insecure employment, career barriers and unsupportive supervisors and organisational cultures – are typical of the issues faced by working mothers in general" (Wright, Crettenden and Skinner, 2016, p. 353); at the same time, they conclude that, in countries where "career progression and greater work responsibilities are tied to spending longer hours at work" (Wright, Crettenden and Skinner, 2016, p. 356), this poses unique challenges for fathers of children with disabilities who are primary breadwinners. Greater financial stress due to costs of raising a child with a disability and the often increased need to contribute to caregiving make the situation particularly challenging for these fathers (Wright, Crettenden and Skinner, 2016).

What is particularly noteworthy about this finding is that it helps to make clear not only the need to engage fathers of children with disabilities but also the necessity to address the structural barriers that inhibit men's ability to contribute to care work. Put another way, this research shows the futility of placing the blame for unengaged fathers solely at the feet of individual fathers. Instead, it demonstrates the need to focus on the broader system and society that have made fatherhood, particularly for fathers of children with disabilities, an optional role that men must opt into intentionally and with some effort rather than being an assumed role for men to inhabit. This means that family-friendly workplace policies are a critical and essential component of increasing positive fatherhood and, in particular, for helping fathers of children with disabilities to contribute more to care work and household duties.

For example, if family-friendly work policies include flexible hours, allow remote work where possible and offer robust paid time off to factor in additional family and medical leave, fathers would have more flexibility to be able to attend medical appointments, which are often frequent and time-consuming for children with disabilities, without fearing repercussions for their jobs and careers. Non-transferrable, paid and ideally mandatory paternity leave is a key policy that must be implemented to set more fathers up for longterm positive involvement, again particularly for fathers of children with disabilities, who may especially benefit from early bonding time. Finally, it is imperative that male leaders in workplaces role-model the utilization of these policies and actively encourage men to use them in order to spearhead the needed social and cultural norm shifts that will make it easier for fathers to equitably share care work.

Fathers can be and want to be involved in raising and caring for their children, and excluding them because of an assumption that they do not want to be involved or stereotyping all men as uninterested in contributing to care work is damaging (Pancsofar, Petroff and Lewis, 2017). In a study comparing fathers of children with and without disabilities based on a nationally representative sample in Australia, 72 per cent of fathers of children with autism spectrum disorder reported that they felt that they needed support but could not get it, compared with

#### **72%**

of fathers of children with autism spectrum disorder reported that they felt that they needed support but could not get it, compared with 63% of fathers of children without a disability 63 per cent of fathers of children without a disability (Seymour, Giallo and Wood, 2020). In a US-based practitioner-focused guide on making school classrooms more father-friendly, the authors note that fathers do not want to feel as though they are assumed to be a less relevant parent, and many fathers specifically note not wanting to receive information about their child's health and condition second-hand (Pancsofar and others, 2019). Furthermore,

some research shows that, because of the amplified stresses facing fathers of children with disabilities, there may also be unique opportunities to see the futility of adhering to harmful notions of masculinity and an opportunity to break out of the constraining "man box" that men are expected to remain within. According to one study examining the experiences of Dutch fathers on fathering children with disabilities, there is an opportunity to help fathers identify "new life perspectives" they have gained from having a child with disabilities, including transforming expectations and maintaining a positive attitude (Schippers and others, 2020).

Many fathers are committed to their children with disabilities. We need to focus more on encouraging positive behaviours than on discouraging negative behaviours.

 A staff member of a UNFPA Country Office

#### Early interventions with fathers

Broader research on fatherhood overwhelmingly supports the necessity of engaging men early in the fatherhood journey, as doing so substantially increases the likelihood that they will remain engaged in the long term. Men who are prepared to take on the role of supportive partners should be encouraged to attend the births of their children; based on the Serbia IMAGES study, for example, only 2.4 per cent of men attend the birth of their child (Hughson, 2018). Indeed, fathers' involvement in antenatal care has proven to be limited, partly due to the failure to engage them in accessible and appropriate ways, compromising the bond between fathers and their children, particularly in cases of children with disabilities. Cultural norms often discourage fathers from taking an active role in perinatal care, and social protection mechanisms make this care financially unfeasible. However, it is important to note that, while research shows that men's involvement during pregnancy and birth can improve the health outcomes and well-being of the baby and the mother, evidence is still mixed concerning the benefits of engaging men in antenatal care, as there is a risk that men could inhibit the rights of the pregnant person in making informed decisions about their care. Still, men often play a significant role in decisions relating to pregnancy care and childbirth, so it is an area where increasing positive and supportive male engagement is warranted (Plan International and Promundo, 2021).

For research specific to experiences of parenting children with disabilities, a US-based longitudinal study examining early childhood predictors of mothers' and fathers' relationships with their adolescent children with developmental disabilities found that relationships were predicted by earlier parenting stress and specifically that "children's early behaviour problems are indicators of potentially deleterious father-teen relationships" (Mitchell and Hauser-Cram, 2010, p. 496). Recognizing that parenting stress and relationship tensions early on between parents and their children with developmental disabilities had negative long-term impacts, the authors offer two key points for intervention:

"First, parenting assistance and support to reduce stress during the early childhood years can benefit both mothers and fathers. Second, helping families and children cope with and diminish problem behaviours is likely to yield multiple advantages for parents and children and deserves emphasis in early intervention and pre-school programmes" (Mitchell and Hauser-Cram, 2010, p. 487). It is important to note that these recommendations are for all parents of children with disabilities, not just fathers.

Particularly in the Eastern Europe and Central Asia region, fathers of children with disabilities are often not included in the initial discussion informing parents of their child's medical diagnosis. This is a key area to increase opportunities for fathers to be involved. In qualitative research concerning fathers of children with disabilities in Ireland, for example, researchers found that fathers are profoundly impacted when they find out that their child has been diagnosed with an intellectual disability. They vividly remember how they were told and who told them. As such, health-care professionals need more training on how to be sensitive to these needs, and fathers need more support at this crucial stage (Marsh, Warren and Savage, 2018). The finding that fathers are profoundly impacted holds tremendous promise in helping fathers to stay engaged in the long term.

Indeed, research suggests that the better a father understands his child's disability, the more likely he is to actively participate in activities and engage with his child (Boyd, Iacono and McDonald, 2019). Fathers of children with disabilities perceive support in planning for their family's future to be particularly important (Boyd, Iacono and McDonald, 2019). An Israel-based study comparing fathers of children with and without learning disabilities concluded that interventions should focus on "enhancing fathers' levels of comprehensibility, manageability, and meaningfulness in stressful situations as well as increasing fathers' awareness regarding the possible potential risks of their own resources and strategies for their children's adjustment. In addition, to enhance the quality of father-child attachment relations, interventions may include strategies for empowering parents to establish a secure base for children with LD [learning disabilities]" (Al-Yagon, 2011, p. 505).

#### Father-child relationship

A child's attachment to their father matters for every child and plays a distinct and complementary role to their attachment to other primary caregivers. As the Israel-based study noted above suggests, this is important for fathers of children with learning disabilities, as they are more vulnerable to insecure attachments (Al-Yagon, 2011). Specifically, the study found that fathers' coping strategies play an important role in the socioemotional adjustment of children with learning disabilities. For example, a higher level of active coping (e.g. more information-seeking and problem-solving) and lower level of avoidant coping (e.g. less denial or escape through food, drugs, etc.) on the part of fathers contributed to a more secure attachment on the part of their children (e.g. their children believed that their father was responsive and available in times of stress), which, in turn, played a mediating role for children's socioemotional adjustment. As such, interventions should focus on building the capacity of fathers of children with and without learning disabilities to cope so that this translates into more secure attachments and improved socioemotional adjustment on the part of their children (Al-Yagon, 2011).

In one of the few studies that took place in the Eastern Europe and Central Asia region, a study in Türkiye compared mothers and fathers of children with disabilities concerning their

style of interaction with their children and their children's subsequent level of engagement. The researcher found that Turkish mothers of children with Down Syndrome and autism are more responsive and show more affection than the fathers of those children. The results also indicated that, regardless of whether a child had Down Syndrome or autism, both the mother's and father's level of responsiveness and affection are important and are associated with a child's engagement; as such, the author concludes that fathers should be supported in building their capacity in these areas to support their children (Karaaslan, 2016).

#### How having a child with disabilities impacts fathers

Research on parents of children with disabilities shows that these parents often experience increased mental-health, physical-health, social and financial challenges than parents of children without disabilities. While research focused on fathers in this area is limited, the available literature suggests that fathers of children with disabilities may be at a greater risk for mental health difficulties than both fathers of children without disabilities and mothers of children with disabilities, although more research is needed in this area. In a study comparing fathers and mothers of children with intellectual disabilities in Australia, for example, fathers of children with intellectual disabilities were found to be at higher risk for mental health difficulties than their female counterparts (Giallo and others, 2015).

A Taiwan-based study comparing fathers of children with and without developmental disabilities found that fathers of children with developmental disabilities experienced poorer mental and physical health–related quality of life and higher parental stress than fathers of children without disabilities (Huang and others, 2014). However, one study comparing fathers of children with and without intellectual disabilities, which drew its data from a UK population-representative and cohort study (the third wave of the Millennium Cohort Study), argued that, based on their findings, fathers of children with disabilities are not inherently at higher risk of poorer outcomes, but there is a need to support all fathers with "children with behavioural problems and living in poverty" (Langley, Totsika and Hastings, 2020, p. 399). In addition, a US-based study on 91 heterosexual (mother–father) families raising children who were either typically developing or had intellectual or developmental disabilities found that there was not a significant difference in the well-being of the mothers and fathers (Glidden and others, 2010).

#### How to support and engage fathers of children with disabilities

The following points are the key conclusions from the literature review on ways to support and engage fathers of children with disabilities; this list is incorporated into the final list of recommendations for UNFPA later in this document.

- There is a great "need for professionals to recognize and respond to specific needs of fathers. Addressing their concerns will enable education, health, and social care policies to be developed that more effectively target the specific support needs of fathers and ensure that these are met. Specific mental health and primary care policies must also take account of and respond to the mental health concerns and issues that fathers experience" (Marsh, Brown and McCann, 2020, p. 87).
- Family support professionals may need special training as it relates to fathers (and families) of children with disabilities and their issues related to parenting and family stress (Darling, Senatore and Strachan, 2012), and support systems, including teachers, should be engaged around the value and importance of involving fathers so that they can help to facilitate their involvement (George and Kanupka, 2019).
- Fathers need support groups and ways to learn more about their child's condition and how they can support them. Parent-focused programmes should also focus on the specific needs of fathers (Rafferty, Tidman and Ekas, 2020).
- Early intervention is key. Helping fathers become involved as early as possible has long-term benefits for fathers, children and co-parents (Laxman and others, 2015). To ensure a long-term positive impact, fathers should be engaged from when their child is born until they reach 5 years of age. Service providers and policymakers should assume that fathers want to opt in to raising their children rather than opt out; they should build fathers' capacity and ascertain their communication preferences (Noggle, 2019). This includes supporting parents in interactions with their children in natural contexts where capacity can be built for all parents (Vilaseca and others, 2020).
- More research and piloting for acceptance-based interventions and other psychological interventions targeting acceptance and avoidance processes (e.g. mindfulness-based approaches, including acceptance and commitment therapy) should be undertaken, as these interventions could be used to positively affect paternal psychological adjustment; they have shown promise in increasing the involvement of fathers in childcare and in improving parent-child relationships and child outcomes (MacDonald and Hastings, 2010; MacDonald, Hastings and Fitzsimons, 2010).



# 3.3 Men as partners: co-parents of children with disabilities and partners of persons with disabilities

Increasing positive involvement on the part of fathers is good for men and their children; it is also highly beneficial for their families and especially their co-parents, such as mothers. As noted in a review of global literature on engaging men through fatherhood,

Encouraging fathers to be more involved in care work benefits fathers as well as their co-parents. [Fathers'] contributions to parenting, and home and family maintenance foster greater maternal satisfaction. Having an involved father can also buffer against the effects of a less supportive mother (e.g., a mother managing depression). Dads who spend more time involved in caring for their children also have better well-being, and are better at expressing emotions and experiencing empathy. Households with parents who have a positive relationship produce a more harmonious home environment, and this fosters children's positive development. (Hansen, Pascoe and Wells, 2022, pp. 8–9)

While the research specific to parents of children with disabilities is limited, the global scoping review of fathers' perceptions and experiences of their role in parenting a child with a developmental disability identified through the review found that there appears to be a positive association between fathers' ability to take part in activities with their children and mothers' reported well-being, and one study in the scoping review "found that fathers who reported higher levels of positive experiences with their child had lower levels of stress reported by their partners" (Boyd, Iacono and McDonald, 2019, p. 318). A study of 243 Polish fathers who were married and had at least one child with disabilities found that the fathers' level of involvement also impacted the well-being, stress levels, etc. of the co-parent (usually the mother) (Brągiel and Kaniok, 2014). Increasing positive involvement on the part of fathers also enables their female partner to have more time and capacity to focus on their own career ambitions, thus further advancing gender equality.

Another area of key importance — but concerning which no research was identified — was the role of men as partners of persons with disabilities. This is a key and urgent area where more research is needed, on how support on the part of a male partner of a person with disabilities impacts their partner's well-being and health outcomes, and on how male partners of persons with disabilities could be engaged as allies in the movement to advance disability equality. One of the specific areas mentioned by regional UNFPA Country Offices was the need to build the economic empowerment of women with disabilities, and the need to engage men as supportive partners in achieving this goal.

### 3.4 Men and boys with disabilities: clients, service users and survivors

Men with disabilities are at higher risk for poorer health outcomes than men without disabilities and have considerable social and economic disadvantages as well (Kavanagh and others, 2016). They also appear at greater risk for thoughts of suicide than men without disabilities (Milner and others, 2019). As noted in the Introduction, men with disabilities have been found to have a significantly lower level of education than men without disabilities and are more often unemployed. More research, particularly in the Eastern Europe and Central Asia region, is needed to understand if the barriers to and issues accessing services, including housing, transportation and care, differ for men and boys with disabilities or if they are similar to what all persons with disabilities experience.

Literature on Men's Sheds offered the most promising programmatic insights from the research focused on men with disabilities (Hansji, Wilson and Cordier, 2015; Wilson and others, 2020). Men's Sheds is an Australian-born community-based organization that has turned into a global movement and could potentially be adopted for the Eastern Europe and Central Asia region. Evidence from studies on Men's Sheds, which covered mentoring between men without disabilities and men with disabilities, showed that Men's Sheds are a valuable and inclusive environment that is particularly promising, as it focuses on what everyone can contribute rather than on what any one person is lacking.

There was also an additional study conducted in Australia that focused specifically on the experiences of rural men with acquired physical disabilities and their experiences as fathers; this was the only piece of literature identified that specifically examined the experiences of fathers with disabilities. Again, it focused only on men with acquired physical disabilities, rendering invisible fathers with other types of impairments and disabilities. Pini and Conway's research (2017) was based on narratives from 16 rural men with an acquired disability and used Gershick and Miller's (1995) typology of reliance, rejection and reformulation to situate the research. Their research highlights the additional challenges that men with disabilities face in poorly resourced settings, whereby they may feel additional pressure to rely on traditional notions of masculinity in order to "compensate" for their disability, and yet they face additional hurdles in finding stable and accessible employment, accessing facilities, and participating in outdoor activities and sports with and without their children.

One of the few areas where one would expect more nuance and focus on the health needs of men with disabilities is literature focused on men's health. However, the health needs of and unique considerations for men with disabilities appear to be lacking in the already limited literature on men's health. For example, Promundo's 2018 *Masculine Norms and Men's Health* report documents men's health through a gender lens globally but does not mention disability (Ragonese, Shand and Barker, 2019). Similarly, the Netherlands-based Knowledge Platform on Sexual and Reproductive Health and associated international network focus explicitly on men's sexual and reproductive health, but their latest position paper does not mention disability.

The sexual and reproductive health needs of men and boys with disabilities seems to be a key area where bias and stereotypes have perpetuated cycles of harm. The literature, particularly from Australia and the works of Wilson and others (2011, 2012), notes that much of the research relating to the sexuality of men with disabilities tends towards pathologizing their sexuality and framing it as a "problem", adding that this needs to change to a more proactive approach. In interviews we conducted, it was noted that the sexual needs of men with disabilities are often framed as an "inevitable problem" that has to be "dealt with", often by employing sex workers. That is, men with disabilities, and in particular men with intellectual disabilities, need support to develop healthy masculine sexuality, need assistance to improve their ability to have healthy and positive human connections with others and need sexuality education. In other words, the health and well-being of men with disabilities, and more research ris needed, particularly men. Unfortunately, no literature was identified on the accessibility of sexual and reproductive health services for men with disabilities, and more research is needed, particularly in Eastern Europe and Central Asia, to understand the gaps and needs in this area.

The fact that men with disabilities are pathologized instead of getting support can also be seen in that much of the literature relating to men with disabilities and sexuality focused on men who had perpetrated sexually abusive behaviours (i.e. sexual offenders) (Sex Offender Treatment Services Collaborative – Intellectual Disabilities, 2010; Hockley and Langdon, 2015; Waugh and others, 2014). The findings from this literature suggested that men who were in treatment as a result of their abuse found group support and therapeutic interventions helpful, and that empathy and perspective-taking were key targets for capacity-building. This research also confirmed that, similar to men without disabilities, men with disabilities who perpetrate abusive sexual behaviours are likely to have been victims of sexual abuse themselves or to have experienced other adverse childhood events. All of the above suggests that much more proactive and primary prevention-focused work could be invested in so as to support men with disabilities in understanding how to find the types of intimacy and human connection that most humans crave and to do so in a way that is based on empathy, compassion and consent.

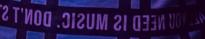
The specific impact of humanitarian emergencies on men and boys, including those with disabilities, is a fairly new area that is just now starting to get attention from the international community (IASC, 2015; IASC, 2019). Likewise, the fact that there are rapidly increasing numbers of war veterans and survivors of armed conflicts in many parts of the region calls for a renewed engagement with the organizations representing these populations to ensure that the response is disability-inclusive and accessible.

# 3.5 Men as allies and agents of positive change: engaging men to advance disability equality

Unfortunately, there is a lack of literature specifically reporting on strategies to engage men as allies and agents of positive change to advance disability equality. This appears to be a key area where more research is needed to understand promising approaches to engaging men, and where advocacy is sorely needed. This document provides numerous strategies and approaches for disability-inclusive development, and efforts to engage male key stakeholders in civil society and government to advance this work is urgently needed. Such efforts include mainstreaming disability issues in the agendas of organizations working on gender equality, sexual and reproductive health, and gender-based violence. Additionally, and as noted in the recommendations below, men need to be engaged as part of public education campaigns, including social norms campaigns and edutainment initiatives, in roles such as being a father of a child with disabilities, being a partner of a person with disabilities, or as a man with a disability beyond just physical and sensory disabilities, as these are the roles that men with disabilities most commonly fill, and it is important to diversify this representation. Men are also highly influenced by their social networks and in particular their own male peers, and efforts to engage men as allies should leverage men's relationships with other men so that men are doing the work of engaging and mobilizing more men.

It is also important to note that, while men and boys can and should be — and indeed many want to be — supportive allies for the rights and empowerment of women and girls, such efforts will have limited efficacy if men are engaged only insofar as they are instrumental to women's empowerment. This is because men need to understand and critically examine the damaging impacts of patriarchal systems on their own lives, and understand the costs of identifying with harmful notions of masculinity and gender-inequitable attitudes so they can develop new notions of care, connection and alternative narratives that ground them outside of the rigid and harmful ideals of dominant masculinity. In doing so, men can become intrinsically motivated as co-beneficiaries and stakeholders in gender and social equality, including disability-inclusive development. As such, engaging men as allies for women and girls with disabilities should happen alongside conversations among men as well as in mixed-gender groups grounded in a gender-transformative framework that helps men (and women) understand the impacts of harmful gender norms.

# SECTION 4 CONCLUSIONS AND RECOMMENDATIONS



STOP . LET'S ROCK ALL'

JNFPA North Macedonia/Tomislav Georgiev

There is an urgent need to engage men as fathers and partners, and men and boys as clients, service users and allies in efforts to advance disability equality. Social norms and cultural contexts, particularly in the Eastern Europe and Central Asia region, create an environment whereby women bear the brunt of the risk and burden of violence, oppression and inequality. Women and girls with disabilities are at particularly high risk for experiencing violence, including stigma and discrimination, and facing barriers to accessing basic services and care, including health care, housing, education, employment and transportation. It is important to remember that such oppression both contributes to and furthers the dehumanization of society's most vulnerable populations, which is a price exacted on everyone's collective humanity. That is, since human beings are a social species that requires connections and relationships with others to survive, the denial of humanity in relation to any one individual strips away at the collective humanity of all.

Men and boys, in particular, are socialized from infancy in ways that actively suppress their basic human needs and capacities for love, connection, compassion and empathy, and in doing so men and boys are taught to perpetuate cycles of harm that denigrate all that is feminine and thus considered "weak" in order to equate dominance with masculine identity (Greene, 2021). In this fragile position of dominance, men and boys are increasingly disconnected from others, and from this place of isolation many double down on dominance in efforts to meet their needs for connection. As the evidence clearly shows, this does not work; it only fuels violence, conflict, inequality and cycles of harm. It hurts men, and it hurts women and children. Society's most vulnerable populations, such as women and girls with disabilities, experience disproportionate hardships as a result of this. Many men and boys with disabilities struggle with the social pressure to conform to masculine and ableist ideals, having to deal with conflicting expectations concerning the gualities that men are expected to possess (e.g. strength, independence) and the reality of having a disability (e.g. the assumption that a disability means weakness and dependence). This social pressure leads to unique mental, social and physical challenges for men and boys with disabilities, as well as for fathers of children with disabilities.

As such, and particularly in relation to marginalized populations such as persons with disabilities, it is imperative to engage men as fathers, partners and allies as well as clients with their own distinct health needs, and as survivors of violence. Based on the findings from the research undertaken for this project, the following recommendations offer key entry points and avenues for engaging and mobilizing men and boys to advance disability equality.

Overall strategies for framing all recommendations:

- Nothing about us without us. The best way to ensure that this occurs is to consult persons with disabilities and their representative organizations at all stages, taking into account the diversity of the disability community. See Appendix A in this document for more specific information about how to go about consulting persons with disabilities.
- Engaging men for gender and social equality, including advancing disability equality for all. Women and girls disproportionately suffer from gender inequality, but harmful gender norms are bad for everyone. Men are also negatively impacted by harmful gender norms and patriarchal systems, and most men actively oppose violence and deeply care about the women and girls in their lives. As such, rather than being cast as a "problem"

in the way of equality, men should be seen as co-beneficiaries and stakeholders in the fight for gender and social equality, and should be perceived as a necessary part of the solution to achieving gender equality.

For a summary of this research (and the research for the subsequent technical report in conflict and post-conflict settings) from a life-cycle perspective, see Appendix B.

## 4.1 Demonstrating political and strategic commitment to disability-inclusive male engagement

UNFPA's high-level commitment to making its work inclusive of and accessible to persons with disabilities, declared in its 2021 Disability Inclusion Strategy, serves as the guiding principle for its policies and programmes. The practical implementation of the Strategy by the Regional Office for Eastern Europe and Central Asia and the Country Offices cannot be underestimated. Specifically, they should give consideration to the following:

- » ensuring full accessibility of their infrastructures, communication and information materials for persons with disabilities
- » establishing strategic long-term partnerships with organizations representing persons with disabilities
- >> conducting disability impact assessments of upcoming programmes and initiatives, such as the MenEngage strategy
- » investing in in-house disability expertise for example, by nominating horizontal disability focal points in Country Offices
- » providing training and support to staff on disability inclusion

At the global level, due consideration to becoming a member of the Global Action on Disability (GLAD) Network should be given in order to provide additional support and visibility to UNFPA's commitment to disability-inclusive development.

The <u>Global Action on Disability Network</u> is a coordination mechanism for bilateral and multilateral donors, foundations, international organizations and disability networks working to achieve disability-inclusive development and humanitarian action. The work of the GLAD Network is guided by the "leave no one behind" principle of the Sustainable Development Goals and the UN Convention on the Rights of Persons with Disabilities. Its activities include sharing expertise, coordinating joint actions and undertaking mutual learning on disability-inclusive development.

A number of UN agencies, such as UNDP, UNICEF and UN Women, are members of the GLAD Network.

## 4.2 Ensuring availability of disabilityinclusive data

Getting good, reliable data is the first building block towards understanding the real situation of women, men and children with disabilities and designing tailored, measurable interventions. It is recommended that UNFPA, in collaboration with the UN country teams, advocate the reform of national data collection systems to make them inclusive of persons with disabilities. The following are of particular relevance:

> the inclusion of the Washington Group Short Set of questions within censuses and other large surveys, such as demographic health surveys, labour force surveys and household surveys

The <u>Washington Group Short Set on Functioning</u> is the most recognized international statistical tool for generating disability data. It includes six questions on hearing, vision, mobility, self-care, cognition and communication that can be answered on a graded scale, enabling policymakers to distinguish between persons with and without disabilities and general comparable data.

- » disaggregation of data by gender, age and disability, particularly in gender-sensitive surveys (e.g. on sexual violence)
- >> monitoring of the national SDG targets in a disability-inclusive manner following, for example, human rights indicators developed by the UN Office of the High Commissioner for Human Rights (OHCHR, 2021)

# 4.3 Recommendations for engaging men as fathers

Supporting fathers of children with disabilities supports children and the broader family unit. However, fathers of children with disabilities need much more support than they are currently receiving, and social and cultural systems and norms need to change in order to facilitate greater positive father involvement. It is important to note that, while efforts to change traditional attitudes about parenting children with disabilities are essential, policy reforms are also needed to destigmatize disability and provide adequate support for children and their families.

In making recommendations in this section, it is important to acknowledge the significant work that is already being done by some UN agencies, such as UNICEF, to support children with disabilities and their families. UNFPA is encouraged to build on that work, while reinforcing inter-agency cooperation with a view to making these efforts disability-inclusive. Additionally, UNFPA is already engaged in valuable evidence-based work that seeks to increase positive father involvement in Eastern Europe and Centra Asia, including through two pilot programmes, Parentsmart and Expanding Choices, focused on expanding gender-responsive policies and practices regarding family-friendly workplaces.

Finally, UNFPA and Promundo (2018) published an advocacy brief that includes key recommendations for engaging men in unpaid care work in Eastern Europe and Central Asia (e.g. expanding paternity leave, supporting work–life balance and working with schools, health-care providers, etc. to create more opportunities for male engagement in early childhood care and teaching) and that can be strengthened with the additional focus on fathers of children with disabilities provided here.

# Recommendations for improving the availability of services for children with disabilities and their families

- Ensure that ethical guidelines and training on disability addressing perinatal health-care professionals that include information about a child's disability are presented in a nonjudgmental and objective way, avoid speculation about the child's expected quality of life and include resources for professional and peer support and guidance.
- Make sure that information is presented to both of a child's parents and, if relevant, other family members. Research shows that fathers value being included in these discussions, as this helps them understand their child's disability.
- Advocate early-identification and intervention services in local communities that offer counselling, referral and coordination of services for children with disabilities.
- Support the development of respite and counselling services for parents and primary caregivers of children with disabilities at the local level. These services may include day-care centres, temporary foster-care arrangements, home help checks and other strategies.
- Increase the availability of inclusive early care and education for children with disabilities.

#### Recommendations on early intervention with fathers

- Explore current practices and social expectations regarding the presence of supportive male partners during birth and immediately post-partum. Increasing opportunities for men (namely fathers-to-be) to play a supportive role during labour, birth and immediately post-partum can strengthen bonds between a pregnant person and their partner and increase the likelihood of long-term positive fatherhood.
- Provide support so fathers become involved as early as possible, as early intervention has long-term benefits for fathers, children and co-parents. Engage fathers from the birth of their child until they reach five years of age in order to have a long-term positive impact. This is emphasized in the UNFPA and Promundo advocacy brief on engaging men in unpaid care work, where they note the need to

[w]ork with school administrators, teachers and other key decisionmakers to further encourage men's involvement with their children in school and day care, and promote that more men become involved in teaching and early childhood care. As the data show, many men are already involved – albeit in limited ways – in the lives of their children. Many fathers care about their children's educational development and want them to succeed in life. Men's involvement in children's education could be a crucial entry point to reach them where they are. (UNFPA and Promundo, 2018)

# Recommendations on engaging fathers and mainstreaming disability equality in resources for parents

- Improve access for fathers of children with disabilities in so-called fathers' clubs and similar initiatives through proactive outreach work and improving accessibility.
- Build the capacity of professionals to understand and address the specific needs of fathers. Family support professionals may need special training concerning fathers (and families) of children with disabilities and their issues related to parenting and family stress, and support systems, including teachers, should be engaged to help to facilitate father involvement.
- Do not assume that fathers want to opt out of parenting; instead, assume that they will opt in if given the support to do so. To encourage fathers to opt in to parenting, build their capacity to cope with stress and to understand the needs of their child with disabilities, and ascertain fathers' communication preferences. This includes supporting parents in interactions with their children in natural contexts where capacity can be built for all parents.
- Meet fathers in places where they naturally congregate, including where their children meet, such as at school, at sports facilities or in health-care settings as well as workplaces, faith-based settings and other settings where men eat, socialize, worship, work and play. In addition, give fathers a compelling "why" story: fathers (of children with or without disabilities) are more likely to get involved in programmes and services if they perceive a clear role for themselves and the impact of their participation, particularly as it relates to positively benefiting their children and the broader family unit.
- Identify opportunities to invite fathers into conversations around their child's care. It was noted in the research both that men are discouraged when they get information about their child's condition or needs second-hand, and also that the more men understand their child's disability and needs, the more likely they are to actively participate in activities and engage with their child.
- Support fathers of children with disabilities in particular in planning for their family's future, and they need support to feel empowered by establishing a secure, loving and responsive connection with their child.
- Support fathers of children with disabilities by building their capacities to cope with and reduce stress (particularly in the early childhood years as a long-term strategy to foster parent-child relationships) and to respond to their child with affection.
- Establish support groups for fathers (such as fathers' clubs), and help them learn more about their child's condition and how they can support them. Parent-focused programmes should also focus on the specific needs of fathers.
- Carry out organizational assessments. It was noted across the research both the written literature and primary research conducted with UNFPA Country Offices – that many of the systems and organizations that serve parents, including parents of children with disabilities, tend to assume a lack of interest and involvement on the part of fathers. While this is understandable given the cultural context, this perspective also perpetuates the absence of fathers. As such, conducting father-friendly organizational

assessments — such as the toolkits produced by the University of California Berkeley<sup>2</sup> or the National Responsible Fatherhood Clearinghouse<sup>3</sup> — would be of great value for institutions and organizations that serve parents. UNFPA could support other organizations in carrying out such assessments and implementing programmes based on the findings. Examples of where such assessments would be helpful include maternal health and antenatal care services as well as schools and disability-focused civil society organizations that provide day-care centres for children with disabilities (and tend to assume the only parent involved will be the mother).

#### Workplace policies and social protection

UNFPA is currently implementing two pilot programmes on gender-responsive familyfriendly policies: the Parentsmart project for employers in Belarus, and the Expanding Choices project in Albania, the Republic of Moldova and Kosovo.<sup>4</sup> These programmes aim to increase knowledge and access to evidence and tools that facilitate good practices for gender-responsive family-friendly policies across government and private sector activities. Additionally, through public campaigns, communications and engagement with business associations, these programmes aim to cultivate an enabling environment for gender equality and gender-responsive family-friendly policies and practices. The following recommendations provide specific considerations for ways that such gender-responsive family-friendly policies and practices could support fathers – and families – of children with disabilities.

- Equal, paid and non-transferrable parental leave for all parents is a key and essential strategy for achieving gender equality. Parental leave is a key, evidence-based and clear strategy to engage men in the early phases of parenthood, which increases the likelihood of long-term positive fatherhood. Ideally, parental leave would be mandatory (or at least incentivized) and would involve non-transferrable leave of at least 12–16 weeks that includes job protection. Fathers of children with disabilities should have the option to take additional leave — and they should be encouraged to do so.
- There is great need for family-friendly workplaces even more so for parents of children with disabilities — and a workplace culture that supports and encourages parents to play an active role in their children's lives is a key way to increase positive father involvement. As noted in the UNDP regional advocacy paper for Europe and Central Asia, there is a need to "enhance and transform current social protection by the states" (UNDP, 2017, p. 5):

University of California Berkeley, School of Social Welfare, "Engagement and Communication Tools". Available at <u>https://calswec.</u> <u>berkeley.edu/father-engagement-and-father-involvement-toolkit/engagement-communication-tools</u> (accessed on 20 March 2023).

National Responsible Fatherhood Clearinghouse, "Father-Friendliness Organizational Self-Assessment Tool". Available at <u>https://www.fatherhood.gov/research-and-resources/father-friendliness-organizational-self-assessment-and-planning-tool</u> (accessed on 20 March 2023).

<sup>4.</sup> All references to Kosovo shall be understood to be in the context of Security Council Resolution 1244 (1999).

This includes investment in expanding and maintaining free social services and supporting infrastructure (such as child-care services, free day-care centres, senior care centres and rehabilitation centres for children with disabilities) and free and secure public transport; promoting social protection to increase [girls'] school enrolment and attendance; introducing nationally appropriate social protection systems and measures for all (including ... social protection floors) and ensure that relevant policies address the challenges faced by women; providing incentives for both [parents'] active participation in child-care, through equalizing conditions for paid maternity, paternity and parental leave; supporting mechanisms to prevent separation of children from their families, including through community-based alternatives to institutional care; ensuring that single-parent families are not rendered "invisible" within the system of social protection; encouraging public and private sector employers to introduce family-friendly working conditions to support women's career prospects and family male involvement (flexible work schedule, teleworking); and introducing the gender dimension into pension reforms to recognize and reward years of unpaid care provided by women. Gender transformative models of care guaranteeing sustainable models of care that do not increase the burden on women and increase women's participation are also required. (UNDP, 2017, p. 33)

# 4.4 Recommendations for engaging men and boys with disabilities

- Emphasize prevention as a tool for achieving sexual and reproductive health rights rather than post-violence services. Invest in and prioritize access to developmentally appropriate, evidence-based, comprehensive sexuality education for men with disabilities so that they can explore their sexuality in healthy ways, develop healthy relationship skills, identify ways to experience intimacy that fit their needs and realities, and do so within a context of consent and care.
- Invest in primary prevention efforts that reduce the likelihood of adverse childhood experiences and sexual abuse experienced by children with disabilities. Such traumatic events increase the likelihood of perpetuating or being victims of violence in later years.
- Explore partnerships with national war veterans' movements as an entry point into disability-inclusive communities led by men. Use the opportunity to support associations of veterans (whose many members will be persons with acquired disabilities) by introducing them to MenEngage topics while engaging them to advocate for disability-inclusive and accessible communities.
- Explore partnerships with Special Olympics (this is already happening in Bosnia and Herzegovina) to engage boys and men around disability equity. However, ensure that the focus of this work is overcoming barriers, not overcoming disabilities.
- Consider investing in or developing fathers' clubs and efforts similar to Men's Sheds, which focus on what men can contribute and have the potential to build connections between men with and without disabilities.

# 4.5 Recommendations for engaging men as partners, allies and agents of positive change

The long-awaited global recognition of the complex and pervasive nature of structural discrimination experienced by women and girls has brought about excellent, innumerable strategies and tools for their empowerment; many of them focus specifically on girls and women with disabilities. While this change is very encouraging, strategies to engage men and boys in the fight for gender equality are lagging somewhat behind. Meaningful engagement of men and boys in this work is a precondition for achieving sustainable outcomes in the future.

- Encourage and mobilize men as partners of persons with disabilities. These efforts could include highlighting partners of persons with disabilities in public campaigns in an effort to destigmatize and support women with disabilities.
- > Highlight the benefits that being an engaged father can have on their partners and children. These efforts could be used to build relationships with feminist and female-led organizations that may be resistant to efforts to engage men, particularly when those efforts relate to persons with disabilities.
- Encourage men to be supportive partners in their wives' career development. For example, men could be encouraged to take on more care work at home in order to help their partner focus on their career.
- Find a compelling reason why men who are politicians and leaders should advance disability equality. In a region with a fertility crisis, for example, increasing support for fathers to help them be involved caregivers could be part of efforts to increase fertility.
- Through targeted communication and programming support, work with men who are community leaders to put issues relevant to gender equality, work-life balance and children with disabilities on the agenda of organizations for persons with disabilities, most of which are led by men with disabilities.

### 4.6 Strategies to engage men around disabilities

The following are strategies that can be used to engage men on disabilities issues.

- Sender-transformative programming: in employing gender-transformative frameworks in programming and initiatives, expand the focus to include engagement around broader human needs and capacities, such as the need for belonging, connection, empathy and compassion. Link these initiatives to instances of bullying and oppression of marginalized populations to clarify that harmful gender norms, and in particular harmful notions of masculinity, perpetuate not only gender inequality but also male-on-male violence and the oppression of others based on race, socioeconomic status, sexual orientation and disability status.
- Social norms campaigns: changing social norms is a key way to change individuals and systems. Key influencers should be leveraged; however, where there are many divisions across ethnic groups, particularly in post-conflict settings, this may mean engaging multiple role models at the nano-level (individual neighbourhoods).

- Edutainment: TV shows and other forms of edutainment that showcase men as partners of persons with disabilities and fathers of children with disabilities.
- Engagement with faith-based communities: incorporating disabilities into the equality framework within conversations with faith-based communities.
- Discussing conflict-based disabilities: given much of the conflict-based trauma experienced by people in the region, alternative forms of justice, such as communitybased transformative justice practices, may provide a welcome alternative that focuses on accountability, healing and transformative learning rather than on punishment. These alternative forms of justice could create opportunities to talk about disabilities caused by conflict.
- Men in paid care work: incentivizing men in paid care work helps to normalize men in roles of care beyond just fatherhood. Such incentives also provide key opportunities to redefine masculinity in a way that includes care, connection, etc.

#### Areas for potential research related to fatherhood, men and disabilities

The following list outlines some areas for potential research that came up in the literature and in interviews with key stakeholders. As much as possible, this research should involve the participation of disability-focused civil society organizations in order to ensure that work on disability equality is done with diverse populations of persons with disabilities.

- Research on the needs and experiences of fathers with disabilities: participatory research with fathers with disabilities (and their co-parents) is needed in order to understand the potential unique needs of this population.
- Research is needed on the family cost of taking care of a person with a disability and how it impacts both men and women. The research should cover the financial, social and emotional costs. The findings can be used to identify more opportunities to increase men's support for their partners and to build the capacity of men to take a more active and positive role in care work.
- Research into the reasons why men separate from their families upon finding out they have or are going to have a child with a disability: The research should look into why they leave and/or barriers to staying, as well as how they could be better supported to stay. As a UNFPA staff member noted, "At this stage, we don't know why [men leave their families when they find out they have a child with a disability]. We need to ask more questions, rather than just shooting in the dark, so we can understand more."

In addition, there are five areas of research proposed by Wilson and others (2012) that could be further explored:

- Fatherhood: in particular the experiences and lives of fathers of children with intellectual disabilities (note that this area does appear to have been more researched since the publication of Wilson and others' 2012 article, although more is still warranted)
- Male physical expression: such as examining why men with intellectual disabilities tend to be more physical in their expression than women with intellectual disabilities, and seeing how to shift the conversation from considering male physical expression problematic to focusing on health and well-being, including research on whether more engagement in sport and other physical activity might reduce the incidence of these behaviours

- Sexual expression on the part of men with disabilities: specifically moving away from pathologizing male sexuality among those with disabilities to a more proactive focus on health and well-being
- Men's health: noting that there is a need for more specific health guidelines for men with intellectual disabilities
- >> Underweight and obesity: looking at the interplay between body mass and gender roles in men and women with intellectual disability

# 4.7 Issues relating to the ongoing humanitarian crisis and war in Ukraine

At the time of writing, the devastating humanitarian crisis as a result of the full-scale invasion of Ukraine by the Russian Federation is ongoing. The long-term impacts of this war on the region, particularly on matters relating to inequalities, masculine norms and disability, remain to be seen. While it is not feasible to make concrete recommendations based on preliminary observations, and a separate effort would be needed to understand and address the disability dimension of masculinity work in the context of the war, we were asked to include some observations in the hope that it would provide guidance for where more investment, research and considerations are needed.<sup>5</sup>

- There is a robust body of research relating to masculinity and the military and conflict situations. Similar research focused on men and masculinity and the intersections of disability in humanitarian settings is needed to better understand this context.
- There will be a great need to address the trauma of the war. For those who actively fought in and/or experienced combat as a result of this war, trauma-informed efforts to help them process their experiences are going to be essential. The social pressure and subsequent shame experienced by any man who resists conscription or tries to leave the country is going to be a critical aspect of social norms and in particular masculine norms that are going to need to be addressed during and in the aftermath of the war.
- The needs of men who acquire disabilities as a result of the war should be addressed within a gender-transformative framework in order to facilitate their healing as well as their ability to empathize and feel intrinsically motivated to act as allies for other equity-seeking groups, such as women and girls with disabilities. How can families with members with disabilities acquired as a result of the war avoid falling back into traditional gender roles whereby women bear a disproportionately high burden of domestic work while men (with disabilities) are seen as the primary or exclusive breadwinners in the household?
- For men with disabilities who do not have official paperwork documenting their disability – and possibly even for those who do – there is still intense social pressure and potential coercion to be conscripted into the military.

<sup>5.</sup> The authors would like to thank Valeriia Taran-Gaiduk, the EU4GE Programme Coordinator at the UNFPA Country Office in Ukraine, who provided insights based on what she has seen and experienced.

- There are high numbers of refugees and internally displaced persons with disabilities or with children with disabilities who will need ongoing support abroad and in-country. How can men be engaged as allies and advocates to support the needs of women and children who had to leave men in their lives behind as a result of the war?
- It may also be an issue that, in cases where women who are in the military and have children under the age of 18, it may be challenging for the fathers of these children to be granted permission to leave the country with their children. How can these fathers be supported?
- Psychosocial support for fathers who acquire a disability as a result of the war, for their partners and for their children is needed.

# **APPENDIX A**

# DISABILITY-INCLUSIVE Programming

The UNFPA Disability Inclusion Strategy stresses that disability-inclusive programming must be at the centre of all its development and humanitarian work at all levels, for it is a precondition to achieving the 2030 Agenda commitments while leaving no one behind.

In order to meaningfully address the rights of persons with disabilities in the programming cycle, such rights must be considered in project design, planning, implementation, monitoring and evaluation, and reporting.

Arsenjeva and Meyer (2020) build on the experiences of a large global EU–UN project, Bridging the Gap II, to add supportive layers to the classical project management cycle that better reflect the unique nature of international development programmes and the political and organizational nuances that inform efforts to disability-mainstream those programmes.

#### The project cycle: entry points for disability mainstreaming



Source: Janina Arsenjeva and Stefan Meyer, Study on the Inclusion of the Rights of Persons with Disabilities in Development Cooperation in the Bridging the Gap II project: Synthesis Report, 2020, p. 10.

## A1 Underlying principles

#### Political commitment to disability-inclusive development

The message sent to the global community via the adoption of the disability-inclusive 2030 Agenda for Sustainable Development and the Sustainable Development Goals is unequivocal and clear: persons with disabilities must not be left behind in global development processes. The commitment to include them is being operationalized in national SDG commitments as well as internationally: the <u>2019 UN Disability Inclusion Strategy (UNDIS)</u> provides solid foundations for making all pillars of the UN inclusive of persons with disabilities.

The 2021 UNFPA Disability Inclusion Strategy contextualizes UNDIS in UNFPA's operational context and supports the disability-inclusive implementation of UNFPA strategies and

programmes, demonstrating a commitment to not leaving persons with disabilities behind in UNFPA's work. Importantly, the comprehensive approach taken in the UNFPA Strategy, focusing on both the internal and the external dimensions of the organization (i.e. organizational culture, expertise and accessibility, and disability-inclusive programming), complete with indicators, serves as a useful guidance tool for the UNFPA Eastern Europe and Central Asia Regional Office and the Country Offices alike.

The international experience of disability-inclusive development warns against expecting quick outcomes once disability-inclusion frameworks have been put in place: Australia was the first donor country to launch a comprehensive disability-inclusion strategy in 2009 and has kept evaluating and finetuning it over the years (Arsenjeva and Meyer, 2020, pp. 13–14). The Australian approach to disability-inclusive development cooperation is now considered a global gold standard that inspires more and more donors to achieve strategic consistency and perseverance.

It must be borne in mind that, while the strategic commitment to mainstreaming disability in programming is essential, such a commitment will not succeed without attention to operational details, sufficient investment and human resources capacity, as the examples of many countries show (Arsenjeva and Meyer, 2020, pp. 13–14).

#### Gender mainstreaming as an inspiring example for disability-inclusive development

"[Research] compares the Austrian Development Cooperation (ADC) approaches to gender mainstreaming and disability mainstreaming to illustrate how modelling disability-mainstreaming efforts after gender-mainstreaming efforts could have a capitalizing effect.

"The ADC strategy on gender equality to implement the EU Gender Action Plan II, makes gender mainstreaming an unmissable requirement of all its programming work. A strong gender perspective is built in the multi-annual and annual work programmes of the Austrian Development Agency [ADA] and include the required steps to achieve 85% compliance ... when measured with the OECD DAC gender marker 1 (gender mainstreaming) or 2 (specific equality target). Additionally, gender issues have been prioritised in staff trainings, including mandatory training.

"Gender is considered an integral and unquestionable element of ADA's project cycle management, is introduced at the earliest stage of any project and is monitored throughout. However, disability enjoys a more limited exposure and buy-in. In the words of ADA staff members,

'There is no genuine disability mainstreaming in ADA yet comparable to gender or environment. Disability is seen as one sub-category of social inclusion, and there are not many projects that target it. There is no [mandatory] DAC marker, no SDG target ... [G]ender is huge in ADA work because there is support. It's a priority and very visible. Disability marker is somewhat understood, but it's picked up much more slowly." (Arsenjeva and others, 2021, p. 15)

#### Pertinent reflections for UNFPA's strategy on engaging men and boys

- (?) Does the MenEngage strategy build on UNFPA's Disability Inclusion Strategy and its four pillars (leadership and strategic planning and management, inclusiveness, programming, and organizational culture)?
- (?) Have UNFPA staff engaged in MenEngage work undergone training on disability inclusion? Do they have access to ongoing support and advice on disability inclusion?

#### Twin-track approach to disability

A twin-track approach to disability-inclusive programming is universally considered the way to achieve good outcomes for women, men and children with disabilities in programmatic activities. Indeed, the UNFPA Disability Inclusion Strategy adopts the twin-track approach as the key tool for achieving disability inclusion. On the one hand, it sets out that disability matters should be systematically included in all UNFPA programmes and activities, both external and internal. On the other hand, it insists that disability-specific actions to address the situations of the particular historical marginalization of persons with disabilities should be broadly promoted (UNFPA, 2021b).

The international community has long advocated for the meticulous application of the twintrack approach to achieving de facto disability equality. In 2016, the UN Committee on the Rights of Persons with Disabilities said the following in relation to women with disabilities:

The obligation to fulfil [human rights] imposes an ongoing and dynamic duty to adopt and apply the measures needed to secure the development, advancement and empowerment of women with disabilities. States parties must adopt a twin track approach through: a) systematically mainstreaming the interests and rights of women and girls with disabilities across all national action plans, strategies and policies concerning women, childhood and disability as well as in sectoral plans concerning, for example: gender equality, health, violence, education, political participation, employment, access to justice and social protection; and b) targeted and monitored action aimed specifically at women with disabilities. A twin track approach is an essential pre-cursor to reducing inequality with regard to participation and enjoyment of rights. (United Nations, Committee on the Rights of Persons with Disabilities, 2016, Article 6)

#### **Disability mainstreaming**

The consistent and systematic approach to integrating disability-responsive measures into the design, implementation, monitoring and evaluation of all policies and programmes (e.g. ensuring non-discrimination, including reasonable accomodation, and striving for accessibility in all programmes and community services).

#### Disability targeted actions

Disability-specific policy and programme initiatives to support the empowerment of persons with disabilities, address specific requirements and close the gap between persons with disabilities and the broader population (e.g. provision of specific support services, specifically addressing disabilityrelated extra costs). Specific policy actions should respect the diversity of persons with disabilities, including their multiple and intersecting identities.

Source: Office of the High Commissioner for Human Rights, "SDG-CRPD resource package: OHCHR and the rights of persons with disabilities", 2021

The UNFPA Disability Inclusion Strategy adopts a twin-track approach to achieve its goals and attain results, with disability matters being systematically included in all UNFPA programmes and activities, including internal practices and organizational structures. Similarly, disability-specific actions are broadly promoted as greatly needed to address situations and conditions of particular marginalization.

Many UNFPA Country Offices have successfully implemented the twin-track approach in their programmes and initiatives: examples include the incorporation of the Washington Group questions on disability in national censuses, the development of sexual and reproductive health services that are fully accessible for girls and women with disabilities, and targeted support for the development and functioning of national networks of women with disabilities.

#### Pertinent reflections for UNFPA's strategy on engaging men and boys

- ⑦ Does the MenEngage strategy include objectives that are specific to persons with disabilities?
- ⑦ Does the MenEngage strategy explicitly consider persons with disabilities as targets, beneficiaries, allies and partners in the achievement of all of its objectives?
- (?) Is the implementation and evaluation framework for the MenEngage strategy disaggregated by disability?

# Participation of persons with disabilities and organizations for persons with disabilities

"Nothing about us without us" is a key principle of the UN Convention on the Rights of Persons with Disabilities and the global disability movement. It is a response to the pervasive history of invisibility, exclusion and disregard for the views and expertise of persons with disabilities worldwide. The motto reminds us that no decisions affecting persons with disabilities should be made without the direct and meaningful participation of persons with disabilities and their representative organizations. The UN Committee on the Rights of Persons with Disabilities reminds us that, in order to ensure meaningful participation, a number of important prerequisites must be fulfilled, including the following:

Understanding the difference between representative organizations of persons with disabilities and other disability organizations. In disability-related issues, organizations led and governed by persons with disabilities should always be given a priority over other entities such as service providers, research institutions, generalist civil society organizations or professional bodies. In seeking to consult persons with disabilities, governments need to limit their outreach to formally registered organizations to the exclusion of informal groups of persons with disabilities (particularly those belonging to marginalized minorities, such as persons with psychosocial disabilities, persons living with HIV/AIDS or LGBTQI+ persons with disabilities). Furthermore, representation within the disability movement must be ensured as well: the views of women, children and people with invisible, multiple or complex disabilities must be proactively sought.

- Working to build the capacity of organizations representing persons with disabilities. As a result of systematic historical exclusion, communicational and environmental barriers and widespread stigma, organizations for persons with disabilities are often marginalized within the national civil society make-up and may need additional support to participate in decision-making. Specific capacity-building programmes benefiting organizations for persons with disabilities, including those in rural areas, may be necessary. These programmes should be seen as a valuable investment in the construction of a healthy, diverse and representative national civil society movement.
- Creating an accessible and inclusive environment for participation of persons with disabilities. In order to involve persons with disabilities in a meaningful manner, it is usually not necessary to make an open call for participation. The decision maker must ensure that all consultation materials and platforms are accessible to persons with disabilities. This includes websites for screen-reader users, texts in easy-to-understand language, videos accompanied by sign language and closed captions, accessible online meetings, etc. Physical meetings must be organized in fully accessible venues within easy reach for persons with reduced mobility.
- Allocating funds for the participation of persons with disabilities. Persons with disabilities always find themselves excluded when the good intention to involve them cannot be realized due to budget shortages. Disability-inclusive projects must earmark funds for expenses such as sign language interpretation, personal assistants for persons with disabilities who need to be accompanied to meetings, accessible hotel rooms (which are often more expensive than inaccessible ones), wheelchair-accessible transportation, etc.

#### Pertinent reflections for UNFPA's strategy on engaging men and boys

- Were organizations representing persons with disabilities consulted in the design of the strategy? Were they provided with reasonable accommodation for meaningful involvement?
- (?) Does the strategy foresee an active role for organizations for persons with disabilities in the implementation of the strategy?
- (?) Do women, men and children with disabilities feature in activities proposed by the strategies in varied roles, including participants, targets, experts, etc.?
- (?) Have resources been allocated for reasonable accommodation and accessibility within the activities to facilitate the meaningful involvement and visibility of persons with disabilities?

### A2 Checklist for disability-inclusive programming



Source: Adapted from ASQ, "What is the plan-do-check-act (PDCA) cycle?" Available at https://asq.org/quality-resources/pdca-cycle.

#### 1. Project identification and conceptualization

Experience shows that incorporating disability aspects into a project is easier during conceptualization than at the planning stage. It is therefore important that a project identification phase include an overview of relevant stakeholders, including persons with disabilities. Baseline studies and surveys must reflect the diversity of persons with disabilities, including women, men and children with disabilities (as applicable); persons with different types of impairments, including those with complex or invisible disabilities; persons in rural and urban areas; as well as specific groups (ethnic minorities, refugees, LGBTQI+, etc.).

While it is important to rely on sources of scientific data, including reports by international and national organizations, NGOs and academia, it is equally essential to establish direct contact with associations representing persons with disabilities and with individuals with disabilities to better understand the relevance of the planned intervention to their communities. In involving persons with disabilities in baseline studies, consideration must always be given to the full accessibility of the process.

Answer these questions:

- >> What data sources are being analysed to conceptualize the future project?
- Does project conceptualization research reflect the twin-track approach to disability that is, does it consider persons with disabilities in the general background research and focus on disability-specific issues?
- Does project conceptualization research include questions concerning the situation of persons with disabilities and the potential impact of the planned initiative on them?

- Are persons with disabilities participating in the conceptualization research as experts, consultants, focus group participants or other collaborators?
- » Are all phases of the conceptualization research accessible to persons with disabilities?

#### 2. Project planning

The formulation of the project goal and objectives must consider its impact — whether intended or accidental — on persons with disabilities, bearing in mind their diversity. At this stage, a decision will be made whether the project will follow a twin-track approach or whether it will be disability-specific or disability-inclusive. To measure progress towards the realization of the commitment to leave no one behind, it is useful to estimate the intended impact of the initiative on persons with disabilities. The disability policy marker of the Organisation for Economic Co-operation and Development's Development Assistance Committee (OECD-DAC) can be a useful tool for measuring the share of disability-inclusive projects in an organization's programming cycle.

The <u>OECD-DAC disability policy marker</u> was introduced in 2018 to track how disability is mainstreamed in development cooperation and humanitarian programmes, thus contributing to monitoring the implementation of the UN Convention on the Rights of Persons with Disabilities. The marker has a scoring system that distinguishes between activities that have disability inclusion as the principal objective (score 2) and activities that have it as a significant objective (score 1). Activities that neither mainstream nor specifically target disability receive a score of 0. The marker is a voluntary tool that can be applied by any organization or country to any programming activity with an SDG focus.

Answer these questions:

- Does the planned project (1) target persons with disabilities specifically, (2) mainstream disability throughout, or (3) does it not consider persons with disabilities?
- » Are there formal or informal guidelines on a disability-inclusive project cycle?
- Is there in-house or external expertise on a disability-inclusive project cycle, such as a disability focal point or a technical task force made up of disability experts?
- Are persons with disabilities involved in the planning phase of the project? Is the process fully accessible to them?
- Does the project take into account the diversity of the disability community, including women and girls with disabilities, persons with disabilities in rural areas, refugees and internally displaced persons with disabilities, persons with invisible disabilities, LGBTQI+ persons with disabilities, etc.?
- » Has any budget been earmarked for disability accessibility and reasonable accommodation?
- » Have quantitative and qualitative indicators been developed to monitor and evaluate disability inclusion in the project?

<b>Examples of indicators for a disability-inclusive programming cycle</b> (adapted from OHCHR 2021)		
Sector	Quantitative indicators	Qualitative indicators
Gender equality	<ul> <li>Number of women and girls with disabilities reached by the initiative in each geographical location where the initiative is present</li> <li>Number and type of national laws on equal pay, parental/carer leave, childcare, work- life balance, etc.</li> </ul>	<ul> <li>Proportion of CSO leadership positions held by women, disaggregated by disability and geographical location</li> <li>Share of men in receipt of parental leave benefits, disaggregated by disability and geographical location</li> </ul>
Violence against women and girls	<ul> <li>Legislation criminalizing, protecting against and preventing all forms of violence, abuse and exploitation with sanctions for perpetrators and effective remedies for victims</li> <li>Statutory requirement to collect data on complaints, investigations and convictions related to violence, abuse and exploitation of persons with disabilities disaggregated by sex, age, disability and form of violence, abuse and exploitation</li> </ul>	<ul> <li>Proportion of population subjected to physical, psychological or sexual violence in the previous 12 months, disaggregated by gender, disability and type of violence</li> <li>Proportion of shelters for victims of violence that are fully accessible to persons with disabilities</li> <li>Proportion of care leavers who have experienced physical violence in the previous 12 months, disaggregated by disability and gender</li> <li>Percentage of people who think that violence between spouses is a private matter and may be acceptable</li> </ul>
Humanitarian settings	<ul> <li>Ratification of international human rights, humanitarian law and environmental treaties relevant to the protection of persons with disabilities in situations of risk and emergencies</li> <li>Statutory requirement to ensure the accessibility of environments, communications, information and services in situations of risk and humanitarian emergencies at all phases: prevention and preparedness, rescue, recovery, reconstruction and reconciliation</li> </ul>	<ul> <li>Proportion of aid recipients with disabilities, compared with the proportion of persons with disabilities in the population, by sex, age and disability</li> <li>Proportion of beneficiaries of economic empowerment and education programmes in the context of a protracted crisis, disaggregated by gender and disability</li> </ul>
Elimination of harmful practices	<ul> <li>Number of training initiatives that include a module on violence, exploitation and abuse against women, men and children with disabilities in the previous 12 months, disaggregated by gender, disability and type of participants</li> </ul>	<ul> <li>Proportion of women who were married or in a union before the age of 15 and before the age of 18, disaggregated by disability</li> </ul>

Source: Adapted from a template in Austrian Development Agency, Persons with disabilities Inclusion: human right and mandate – Guideline on including persons with disabilities in ADC project cycle management (Vienna, 2013)

#### 3. Project implementation and monitoring

Experience shows that project implementation is often the phase when mainstreaming commitments tend to dissipate or are overlooked as a result of other demands on the project managers and participants: tight deadlines, insufficient budgets, unforeseen circumstances, as well as limited knowledge about disability inclusion and difficulties reaching out to persons with disabilities are all contributing factors.

"We don't complete the circle. The screening works well at the beginning but then drops off the priority list due to limited resources." – donor country representative (Arsenjeva, 2020, p. 11)

Technical project staff — whose primary field of expertise is usually not disability — have requested both resources and ongoing support to ensure that the commitment to a disability-inclusive project is realized throughout the project management cycle.

Answer these questions:

- » Is the Regional Office / Country Office disability focal point involved throughout the project?
- » Are organizations for persons with disabilities involved in monitoring project activities?
- Is there room to adapt project activities if the ongoing monitoring results indicate that the original approach is not fully inclusive of persons with disabilities in practice?
- Are the project communication tools disability-inclusive? Do they use publicity materials that are relatable to those members of the target audience who have a disability?

#### 4. Project evaluation

A project evaluation comprises a mostly qualitative assessment of the project's activities and its intended and unintended outcomes for the target groups. A comprehensive and well-organized evaluation that includes participatory methodologies is essential to ensuring long-term sustainability of the project's results and improving future programming.

Answer these questions:

- » Were all activities conducted as part of the project accessible to persons with disabilities?
- What percentage of the overall project budget was spent on the inclusion of persons with disabilities?
- » Have partnerships between persons with disabilities and their organizations and other project participants been established or reinforced?
- » Were the original project objectives set out at the planning phase achieved?
- » How are persons with disabilities involved in the evaluation of the project?
- » Is it possible to capitalize on, multiply and transfer project outcomes to other contexts?

## **APPENDIX B**

# ENGAGING MEN AND BOYS: A LIFE-CYCLE SUMMARY OF KEY ENTRY POINTS

The following summary highlights key issues and entry points across the life cycle for disability-inclusive work with men and boys to advance gender equality. It pulls from two literature reviews completed on behalf of the UNFPA Eastern Europe and Central Asia Regional Office in 2022. The first literature review, completed in March 2022, looked at how to mainstream disability inclusiveness in work with men and boys for gender equality; the second literature review examined the intersections of masculinities and disabilities in conflict and post-conflict settings for the purposes of advancing disability-inclusive gender equality. This summary was requested in order to synthesize, from these literature reviews, what is known about masculinities and disability at different stages of life, with the aim of understanding how to improve disability-inclusive engagement of men and boys for gender equality and sexual and reproductive health and rights for all.

The literature has been organized by life stages, with the following key stages included. The ages are indicative.

- » Young child: 0-5 years of age
- » Child: 5–17 years of age
- » Parent-child or father-child dyad
- » Adolescent / young adult: 18-25 years of age
- » Adult: 25–59 years of age
- » Older adult: 60+ years of age

Some articles in the literature review also focused on institutions that target particular life stages, such as schools: these are included alongside the appropriate life-course stage.

### **B1** Young child

Literature specifying the needs of children 0-5 was sparse, and the focus was more on what needs to happen to better involve fathers. Fathers should be engaged from birth until their child is 5 years of age in order to have a long-term positive impact. Men should be encouraged to play an active role in perinatal care and to attend the birth of their child, and fathers should be invited to take part in discussions about their child with disabilities so they can understand and feel more comfortable providing care. Other recommendations for early interventions taken from the first literature review include the following:

- Ensure that ethical guidelines and training on disability addressing perinatal health-care professionals that include information about a child's disability are presented in a non-judgmental and objective way, avoid speculation about the child's expected quality of life and include resources for professional and peer support and guidance.
- Make sure that information is presented to both of a child's parents and, if relevant, other family members. Research shows that fathers value being included in these discussions, as this helps them understand their child's disability.
- Advocate early-identification and intervention services in local communities that offer counselling, referral and coordination of services for children with disabilities.
- Increase the availability of inclusive early care and education for children with disabilities.
- Introduce gender-transformative social-emotional learning programming to build skills for emotional regulation and resilience.

## B2 Child

During this life stage, the priorities are to build the capacity of children's caregivers so that they can be actively involved in caring for their child and supporting their child's growth and development, and to ensure that the child has access to disability-inclusive and gendertransformative services and supports that meet their needs. Priorities include the following:

- Make diagnosing disability and receiving government aid to support those with disabilities as straightforward as possible.
- Introduce gender-transformative social-emotional learning and other gender-responsive education that supports resilience and builds skills to manage and positively navigate conflict, advances disability inclusiveness, develops healthy and meaningful relationships with others, and embraces and enacts gender-equitable attitudes and behaviours. Key entry points are where men and boys already congregate, including in schools and around sports.
- » Examine bullying of children with disabilities. Interventions could include those that address and prevent bullying and promote belonging and inclusion for all people.
- Invest in and prioritize access to developmentally appropriate, evidence-based, comprehensive sexuality education for all, including men with disabilities so that they can explore their sexuality in healthy ways (including discussions of sexual pleasure both for themselves and for their partners), develop healthy relationship skills, identify ways to experience intimacy that fit their needs and realities, and do so within a context of consent and care. Investing in and prioritizing access is particularly important for those who may require assistance with movement and bodily functions and thus may relate to the notion of consent differently.
- Invest in primary prevention efforts that reduce the likelihood of adverse childhood experiences and sexual abuse experienced by children with disabilities. Such traumatic events increase the likelihood of perpetuating or being victims of violence in later years.
- Efforts to understand male physical expression, such as examining why men with intellectual disabilities tend to be more physical in their expression than women with intellectual disabilities and seeing how to shift the conversation from considering male physical expression problematic to focusing on health and well-being, including conducting research on whether more engagement in sport and other physical activity might reduce the incidence of these behaviours (Wilson and others, 2012).
- For children in conflict or post-conflict settings, it is important to provide traumainformed support and services to help minimize psychosocial stress and disability. For example, Raslan, Hamlet and Kumari (2021) looked at Syrian children registered in a mental health and psychosocial support project to determine protection concerns and intervention outcomes. Not surprisingly, the authors found that children of all genders had a high chance (74.5 per cent) of at least one psychosocial deprivation.

# B3 Parent-child dyad and male caregivers of persons with disabilities

The review discovered substantial research that dealt with the experiences, needs and desires of parents of children with disabilities and particularly (given the scope of this research) fathers of children with disabilities. Many of the recommendations below are taken from the first literature review, and additional recommendations have been added to emphasize the importance of men increasingly recognizing their role in helping care for other family members with disabilities and not just leaving this care to women:

- Support the development of respite and counselling services for parents and primary caregivers of children with disabilities at the local level. These services may include day-care centres, temporary foster-care arrangements, home help checks and other strategies.
- Improve access for fathers of children with disabilities in so-called fathers' clubs and similar initiatives through proactive outreach work and improving accessibility.
- Build the capacity of professionals to understand and address the specific needs of fathers. Family support professionals may need special training concerning fathers (and families) of children with disabilities and their issues related to parenting and family stress.
- Do not assume that fathers want to opt out of parenting; instead, assume that they will opt in if given the support to do so. To encourage fathers to opt in to parenting, build their capacity to cope with stress and to understand the needs of their child with disabilities, and ascertain fathers' communication preferences. This includes supporting parents in interactions with their children in natural contexts where capacity can be built for all parents.
- Meet fathers in places where they naturally congregate, including places where their children meet, such as at school, at sports facilities, in health-care settings as well as at workplaces, in faith-based settings and in other settings where men eat, socialize, worship, work and play. In addition, give fathers a compelling "why" story: fathers (of children with or without disabilities) are more likely to get involved in programmes and services if they perceive a clear role for themselves and the impact of their participation, particularly as it relates to positively benefiting their children and the broader family unit.
- Identify opportunities to invite fathers into conversations around their child's care. It was noted in the research both that men are discouraged when they get information about their child's condition or needs second-hand, and also that the more men understand their child's disability and needs, the more likely they are to actively participate in activities and engage with their child.
- Support fathers of children with disabilities in particular in planning for their family's future, and they need support to feel empowered by establishing a secure, loving and responsive connection with their child.
- Support fathers of children with disabilities by building their capacities to cope with and reduce stress (particularly in the early childhood years as a long-term strategy to foster parent-child relationships) and to respond to their child with affection.

- Establish support groups for fathers (like fathers' clubs), and help them learn more about their child's condition and how they can support them. Parent-focused programmes should also focus on the specific needs of fathers.
- Carry out organizational assessments. It was noted across the research both the written literature and primary research conducted with UNFPA Country Offices that many of the systems and organizations that serve parents, including parents of children with disabilities, tend to assume a lack of interest and involvement on the part of fathers. While this is understandable given the cultural context, this perspective also perpetuates the absence of fathers. As such, conducting father-friendly organizational assessments such as the toolkits produced by the University of California Berkeley<sup>6</sup> or the National Responsible Fatherhood Clearinghouse<sup>7</sup> would be of great value for institutions and organizations that serve parents. UNFPA could support other organizations in carrying out such assessments and implementing programmes based on the findings. Examples of where such assessments would be helpful include maternal health and antenatal care services as well as schools and disability-focused civil society organizations that provide day-care centres for children with disabilities (and tend to assume the only parent involved will be the mother).
- Identify opportunities for men to learn more about the importance of and logistics for caring for other family members with disabilities, including their own ageing parents, and to take on more of this care work. This should include role-modelling for younger children in order to normalize the idea that men also share in the work of caring for all family members with disabilities.

#### Schools

Increase support for fathers' involvement in schools and classrooms.<sup>8</sup> For example:

"Work with school administrators, teachers and other key decision makers to further encourage men's involvement with their children in school and day care, and promote that more men become involved in teaching and early childhood care. As the data show, many men are already involved – albeit in limited ways – in the lives of their children. Many fathers care about their children's educational development and want them to succeed in life. Men's involvement in children's education could be a crucial entry point to reach them where they are" (UNFPA and Promundo, 2018).

<sup>6.</sup> University of California Berkeley, School of Social Welfare, "Engagement and Communication Tools".

<sup>7.</sup> National Responsible Fatherhood Clearinghouse, "Father-Friendliness Organizational Self-Assessment Tool".

<sup>8.</sup> For other resources on increasing father engagement and building father-friendly classrooms, see George and Kanupka, 2019; Noggle, 2019; Pancsofar, Petroff and Lewis, 2017; and Pancsofar and others, 2019.

# **B4** Adolescent/young adult

Adolescence is a critical time for reaching men and boys, as it is a formative period when gender norms are forged. Experiencing (witnessing or perpetrating) violence during adolescence is a significant predictor of future intimate partner violence. In order to support disability-inclusive engagement of men and boys, the recommendations targeting the life stage of adolescence and youth include the following:

- Provide evidence-based comprehensive sexuality education for young men with disabilities (see the "Child" section of this appendix for more information; Wilson and others, 2011) as well as interventions that build healthy relationships and positive communication skills.
- Introduce gender-transformative social-emotional learning and other gender-responsive education that supports resilience and builds skills to manage and positively navigate conflict, advance disability inclusiveness, develop healthy and meaningful relationships with others, and embrace and enact gender-equitable attitudes and behaviours. Key entry points are where adolescents and other young people already congregate, including in schools, at sports facilities and at workplaces.
- Establish mentor-mentee relationships for men with disabilities, such as those established through Men's Sheds (Wilson and others, 2020).
- » Organize edutainment and social norms campaigns to promote disability-inclusive gender equality and norms.
- Incentivize men in paid care work: doing so helps to normalize men in caregiver roles beyond fatherhood. It also provides a key opportunity to redefine masculinity in a way that includes care, connection, etc.
- Better address the health needs of men with disabilities, including through policies laws to meet their needs. For example, there is a need for more specific health guidelines for men with intellectual disabilities (Wilson and others, 2012).
- Provide mental health services and supports for young men, particularly those in conflict and post-conflict situations to process trauma and post-traumatic stress disorder. For example, a study on Syrian children taking part in a mental health and psychosocial support project to determine protection concerns and intervention outcomes found that, among other concerns, adolescents (particularly male) were more likely to "exhibit aggressive behaviour and educational decline" (Raslan and others, 2021, p. 1).

#### Militarized masculinities, war, post-conflict situations

As 18 is the age when young men can enlist or be conscripted to serve in their country's military, adolescence is a key life stage for challenging harmful gender norms and increasing disability-inclusive understandings of gender. Gender-transformative programmes that reach men in places where they already gather should challenge harmful norms and stereotypes around masculinity and disabilities. A <u>dedicated brief</u> has been developed on disability-inclusive approaches to engaging men and boys in conflict and post-conflict settings.

## **B5** Adult

The majority of the literature reviewed dealt with this life stage, in particular issues relating to adult men with disabilities, including disabled veterans as well as fathers of children with disabilities and partners of persons with disabilities.

Issues to address include the following:

- Streamlining disability diagnosis and applications for benefits so that no persons with disabilities experience added stress and disability-related pain as a result of accessing services (Moreno and others, 2019).
- Continued efforts to engage men in gender-transformative programmes and initiatives that advance gender equality by changing behaviours, norms, systems and institutions. Such efforts are needed because research shows that many men with disabilities (and in particular male disabled veterans) struggle to meet traditional expectations in terms of manhood and gender roles and that this leads to more depression, despair, family breakdown and a struggle to find work. On the other hand, those who are able to embrace more flexible gender roles are better equipped to cope, including in terms of financial security and more peaceful relationships (Naujoks and Lawn, 2018).
- Comorbidities that reduce quality of life, increase stress and increase the likelihood of negative health and social outcomes. Comorbidities start to compound one another in adulthood in those with disabilities; research among disabled male veterans shows a significant amount of untreated post-traumatic stress disorder and other mental health issues, leading to a host of negative interpersonal, health and economic challenges (including intimate partner violence, increased experiences of pain, comorbidities and unemployment). Supporting men in addressing these comorbidities (and preventing them where possible) and integrating this support into a gender-transformative approach that helps men dismantle and reconstruct male gender norms will reduce violence, improve health and advance gender equality.
- Mental health services and supports, including those that support men in processing sexual trauma. We know from evidence elsewhere that men's mental health suffers from adherence to harmful gender norms. Specifically, we know that subscribing to hegemonic masculinity is associated with an increased likelihood of depression, substance abuse and other risky behaviour, sexual harassment and violence against women, and suicide (Ragonese, Shand and Barker, 2019). For male disabled veterans, living in such extreme contradictions between hegemonic and/or militarized masculinities and one's embodied experience either becomes a breaking point for reexamining these norms and embracing norms that are more gender-equitable, or it may result in exacerbated negative impacts on themselves and those around them.
- Particularly for disabled veterans, opportunities for peer support, buddy systems and networking as "increased social support acts as a buffer against pain intensity in individuals with a functional disability" (Sheffler and others, 2016, p. 1209).
- The need to address men's health, as there is a need for more specific health guidelines for men with intellectual disabilities (Wilson and others, 2012).
- Engagement with faith-based communities: incorporating disabilities into an equality framework within conversations with faith-based communities – for example, an

intervention in Iraq (a conflict-affected environment) that sought to advance gender justice through work with women with disabilities (male faith gatekeepers are involved in this work) (Randeree, 2014).

- Alternative forms of justice, such as community-based transformative justice practices, may provide a welcome alternative that focuses on accountability, healing and transformative learning rather than on punishment. Given the amount of conflict-based trauma in the region, these spaces could create opportunities to talk about disabilities that were products of conflict.
- Partnerships with national war veterans' movements as an entry point into disabilityinclusive communities led by men: use the opportunity to support associations of veterans (many of whose members will have acquired disabilities) by introducing them to MenEngage topics while engaging them to advocate for disability-inclusive and accessible communities.
- More efforts are needed to engage and mobilize men as partners of persons with disabilities. Such engagement could include highlighting the partners of persons with disabilities in public campaigns in an effort to destigmatize and support women with disabilities.
- More efforts to engage and mobilize men as caregivers of family members with disabilities, including aging parents. Such efforts could include building men's capacity to care for family members as well as helping men embrace these roles as part of supporting their family and advancing gender equality.
- Very little research currently exists around the needs and experiences of fathers with disabilities: participatory research with fathers with disabilities (and their co-parents) is needed in order to understand the potential unique needs of this population.
- » Fathers with disabilities also need equal, paid, non-transferrable paternity leave with job protection.
- Sender-responsive policies on family-friendly workplaces, which are particularly important for parents of children with disabilities who have to deal with additional costs, medical appointments and logistical barriers in caring for their child.
- Men as politicians and leaders: find a compelling reason why men as politicians and leaders should advance disability equality. Efforts to find this reason could include focusing on the fertility crisis in the region and the need for increased support to involve fathers as caregivers in an effort to increase fertility, etc.
- Men as community leaders: through targeted communication and programming support, put issues relevant to gender equality, work-life balance and children with disabilities on the agenda of organizations for persons with disabilities, most of which are led by men with disabilities.

## **B6 Older adult**

Older persons with disabilities have issues with comorbidities and are at risk of increased psychosocial distress, particularly in conflict settings (Summers and others, 2019). A case study about supported participation of older men with lifelong disabilities at community-based Men's Sheds in Australia concluded that such community spaces are key to reaching older men with disabilities and meeting their social needs, provided appropriate support is available (Wilson and others, 2015).

Efforts should also be made to help men increase their responsibility for and roles in caring for ageing populations, namely older family members with disabilities. Men should also be encouraged and incentivized to train for roles as paid care workers, including those providing care for ageing populations.

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