Disability Prevention Efforts and Disability Rights: Finding Common Ground on Immunization Efforts

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Key Points

• **Universal childhood immunization must reach every child**, including the estimated 150 million infants and children aged under 5 years who live with a disability.¹ If children with disabilities are not included in immunization efforts, universal childhood immunization will not be attained and major initiatives, such as the Millennium Development Goal 4 to reduce child mortality² will not be met.

• **Health care, including immunization efforts, is a right guaranteed for all children**, including children with disabilities, as stated in the Convention on the Rights of the Child³ and the Convention on the Rights of Persons with Disabilities passed in 2006 and now ratified by over 100 countries.⁴

• **Immunization and disability are inextricably linked.** There are both direct and indirect feedback loops between immunization and disability. Immunization can eliminate or mitigate some forms of preventable impairments and disabilities, but it is no less important for a child who is born with a disability or acquires a disability after birth.

• **Disability alone is not a contraindication for immunization.** The majority of children with disabilities should receive immunizations and in the case of contraindications, clear guidelines should be published.

• **Improving access to immunization for children with disabilities will give them a healthier start in life** allowing them to avoid preventable illnesses, further disablement or death.⁵

• **Immunization not only protects children from vaccine preventable diseases, it also serves as an opportunity to deliver other lifesaving measures**, such as vitamin A supplements to prevent malnutrition, insecticide treated nets for protection against malaria, deworming medicine for worms infestation, and provides a platform to promote birth registration.

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• **Adolescents and adults with disabilities must not be forgotten in immunization efforts.** In line with the goal of the Global Immunization Visions and Strategy (GIVS) to immunize more people, the benefits of immunization are increasingly being extended across the lifespan to include adolescents and adults, providing protection against life-threatening diseases such as influenza, meningitis, and cancers. For example, it should be a priority to ensure they are included in the introduction of new vaccines such as the HPV vaccine.

• **Collaboration between the health and disability agendas is critical** to ensure immunization efforts, including strategic communications, are disability-friendly, do not further stigmatize and reach the parents and caregivers, as well as the children with disabilities.

• **Disabled peoples’ organizations (DPOs) and organizations of parents of children with disabilities should be called upon to provide significant collaboration, assistance and guidance** to UNICEF and partners in order to ensure that children with disabilities and their families, as well as parents who have disabilities, are effectively informed and included in all immunization efforts.

• **More and better evidence is needed.** While there is limited evidence regarding the immunization of children with disabilities, initial data shows that children and adolescents with disabilities are at a significant risk of not being included in immunization efforts in a timely and effective manner and are consequently at an increased risk of preventable illness and death.  

  
  All data collected on immunization should be disaggregated and further information should be collected on barriers to access immunization for children with disabilities, as part of general research to improve global immunizations efforts.

**Introduction**

There are both direct and indirect feedback loops between immunization and disability. Immunizations, the majority of which are administered in the first year of life, can eliminate or mitigate many preventable illnesses that can lead to long-term impairments and disabilities. However, immunization is no less important for a child who is born with a disability or who acquires their disability later in life. Improving access to immunization for children with disabilities can help give them a healthier start in life and allow them to avoid preventable illness, further disablement or death.  

As outlined in the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD), children with disabilities shall be ensured “the full enjoyment of human rights and fundamental freedoms on an equal basis with other children”\(^6\), they have the inherent right to life\(^7\), and the enjoyment of the highest attainable standard of health without discrimination on the basis of disability\(^8\). While the right of children to survival and development is a fundamental principal which underlies the CRC,  

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\(^{6}\) ibid  
\(^{7}\) WHO. 2011. World Report on Disability. Ibid.  
\(^{9}\) Ibid, CRPD Article 10.  
\(^{10}\) Ibid, CRPD Article 25
too often the health and well-being of children with disabilities have not been considered part of mainstream efforts.

As stated in the CRPD, people with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. This approach is based on the ‘social model’ of disability, which has replaced the older ‘medical model’ that saw disability as a result solely of the individual’s physical, sensory, intellectual or mental health impairment.

Lack of access to mainstream health services for children with disabilities is due to a variety of environmental factors including adverse policies, negative attitudes, lack of service provision, lack of accessible services, inadequate funding, lack of consultation, lack of involvement and stigma and prejudice. Limited knowledge about disability and related negative attitudes can result in the marginalisation of children with disabilities within their families, schools and communities. In cultures where guilt, shame and fear are associated with the birth of a child with a disability they are frequently hidden from view, ill-treated, and excluded from activities that are crucial for their development. Furthermore, numerous health issues found among children with disabilities may be attributable to restricted access to basic health-related resources like clean water, bed nets and nutrient rich foods.

Some children with disabilities may be more vulnerable to discrimination and social exclusion than others, due to multiple disadvantages arising from impairment, age, gender or social status. Other influential factors may include geographic location (living in rural, disperse areas), belonging to a minority language group and/or found in conflict zones or areas of natural disaster. For example girls with disabilities can be particularly at risk of being discriminated against, as well as children from poorer households and those from minority ethnic groups.

In the past, when the health needs of children with disabilities have been considered, their needs are usually addressed only after the needs of children without disabilities are provided for or addressed through separate, small and often underfunded efforts or pilot programmes. These approaches do not provide equitable access to health care for this large and often

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17 Ibid.


overlooked population. A growing body of data shows that the number of children with disabilities is too large not to be considered when planning mainstream child health initiatives. According to the recent WHO World Report on Disability over 1 billion people worldwide, or approximately 15% of the world’s population, live with a disability, including an estimated 150 million children aged under the age of 5.

The Situation Today

Immunization as a Health Priority

Immunization is a critical component of global efforts to reduce childhood morbidity and mortality. Immunisations are among the most successful and cost-effective of all public health interventions, and have the strong potential to reduce mortality and morbidity rates, particularly for children under five years of age. For this reason, immunization has been a cornerstone of national and international health initiatives.

More children than ever before are being reached with immunization. For example, since 1988, the incidence of polio has fallen by 99%, from more than 350,000 cases to 1,410 cases in 2010, with only four countries remaining endemic – Afghanistan, India, Nigeria and Pakistan – down from more than 125 countries in 1988. DPT3 coverage reached 85% of all children by 2010 and accelerated immunization efforts for measles had decreased mortality by 78% between 2000 and 2008. But there is still a considerable way to go. For example, over a million infants and young children still die annually from pneumococcal disease and rotavirus diarrhoea. A large number of these deaths can be prevented through vaccination.

Children with Disabilities are being Left Out

Unfortunately, millions of children who are born with a disability or who acquire a disability later in life are not among the children who are benefiting from immunization, even in countries where overall immunization rates have increased dramatically.

Part of the problem has been conceptual. In many societies, it is often assumed, both by parents, community members, and not infrequently by health professionals that a child with a disability is not at risk for another major health problem. As one mother in Nepal confided to a researcher recently, ‘God wouldn’t make my child have an intellectual disability and then give him polio.’ Moreover, stigma and discrimination in many societies often make children with disabilities be considered second class citizens, with families and communities hesitating or refusing to allocate needed resources or social supports to ensure their health, well-being or in more extreme cases, their long-term survival.

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26 WHO ibid.
It is a fact that children with disabilities are at the same risk of acquiring childhood diseases as their peers without disabilities, and if children with disabilities are left unimmunized or only partially immunized, the results can be:

- Poorer health outcomes;
- Missing or delay in reaching developmental milestones;
- Avoidable secondary conditions or disabilities;
- They may themselves become carriers for communicable diseases, such as polio;
- In extreme circumstances, preventable death.

There is a lack of awareness among health professionals about the need of immunization for children with disabilities. In reviewing the literature on children who acquire impairments as a result of a disease such as polio or measles, the appearance of such a child is seen as a way of motivating health care workers to redouble their efforts to increase immunization rates. However, little attention is paid to the child who already has a disability, either to ensure that the child is immunized against other diseases or has access to the services needed.28

Even where a child’s impairment does not exclude that child from receiving a vaccination at birth, for example where BCG coverage is more than 95%, disability appears to play a significant factor in drop-outs for subsequent doses. This could be attributed to a lack of awareness among health workers as well as parents and caregivers.

Looking forward, access to health care for children with disabilities, including immunization is a concern that will only increase in the coming years. While improved child health care has significantly reduced the number of children with disabilities through preventable infectious diseases, improved access to health care has also led to an increase in the number of children living with disabilities due to improved neonatal care, better emergency services, and increased access to general paediatric care. The numbers of children with disabilities in high income and increasingly in middle-income countries, indicates that the actual number of children with disabilities will not be significantly reduced in the foreseeable future. In order to ensure that these children are kept as healthy as possible, access to basic health care, including immunizations, will continue to be important.

Moreover, the consequences of not immunizing children with disabilities have implications not only for these children themselves, but for the next generation. For example, the majority of girls with disabilities will grow up to be mothers and have children of their own.29,30 If these women have not been immunized in childhood against diseases such as measles, the risk posed to their own children in utero will be significantly higher.

**Immunization Rates among Children with Disabilities: A Limited Database**

Little research exists globally on the health of children with disabilities beyond their impairment-specific needs and even less is known about immunization rates or practices for children with disabilities. The few studies that do exist point to significantly lower immunization rates for children with disabilities than for their peers without disabilities, even in developed countries with good overall immunization rates.\(^{31}\),\(^{32}\)

A Canadian study found that children with disabilities had significantly lower immunization rates, despite free immunizations available through the Canadian national health system.\(^{33}\) A study of 120 children with spina bifida in the United States found significant underimmunization despite their having an identified source of primary care.\(^{34}\)

Researchers hypothesize that particularly in developing countries, impoverished parents may forego health care for children with disabilities, instead of allocating scarce resources to nonchildren with disabilities or pressing household needs.\(^{35}\) Childhood immunization rates among children with disabilities have been cited as an area of particular concern in such communities.\(^{36}\),\(^{37}\)

Not all studies however show unequal access to immunization. For example, a small-scale study of immunization rates of children with disabilities in an impoverished rural community in Ecuador unexpectedly found comparable rates of immunization among children with disabilities and their non-disabled siblings. This is likely attributed to positive local community attitudes towards persons with disabilities, which led to strong caregiver demand for equal access to immunizations as well as an effective national immunization program.

**Addressing Disability Rights and Prevention as One**

Historically, there has been a lack of interface between immunization efforts and disability issues that has been compounded by tension between health care professionals and the disability rights community. It is a tension of which many in the health care community remain largely unaware, although many leading scholars and advocates in the disability rights community consider it a highly contested and deeply politicized.\(^{39}\)

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\(^{31}\) WHO/World Bank. World Report on Disability. Ibid.


\(^{33}\) Tervo, R., & Taylor, B. Vaccinations and the physically handicapped child. Canadian Medical Association (CMAJ); 1982; 127:474-476.


The debate has been framed by the concern that disability prevention around practices such as pre-natal screening and therapeutic abortion invasive surgery and aggressive medication, when undertaken without the understanding of, or against the wishes of the individuals with disabilities, detract from the overall objective of removing disability discrimination and oppression. In keeping with this line of argument, prevention efforts are problematic as they deny the right of people with disabilities to be themselves. However, it is important to emphasize that not all disability scholars and advocates are against medical interventions that prevent disability. And the International Disability Alliance (IDA), a consortium of leading disability advocacy organizations, has recently prepared a background document specifically addressing the fact that not only do they not see a conflict between disability and immunization efforts but that access to immunizations are an inherent right for all children with disabilities as part of the more general right of access to health.

Debates for and against disability prevention have taken place largely among scholars from developed countries commenting on advanced medical procedures (i.e. prenatal screening, genetic testing). This debate has evolved from the earlier 19th and 20th century eugenics movement, that took a heavy toll on the rights, autonomy, and very lives of people with disabilities in developed countries. However, few of the prominent scholars or advocates involved in these current debates have grown up in countries where morbidity and mortality associated with infectious diseases are leading causes of impairments, nor has much attention been directed specifically towards immunization.

From the perspective of a low or middle-income country, prevention of diseases that can lead to impairments, disability or death through low-cost, low-tech vaccination programmes, are part of general public health efforts. Moreover, equal access to immunization can be considered a component of the ‘right to health’ guaranteed to all children with disabilities under the CRPD and CRC and in line with the MDGs. Using this rationale it is the right to health which is drawing increasing attention from both the global health and the global disability communities and this provides a common ground from which to move the agenda forward.

**Inclusive Immunization as an Entry Point for Additional Health Outcomes**

Immunization not only protects children from vaccine-preventable diseases, but also serves as an opportunity to deliver other life-saving measures, such as vitamin A supplements to prevent malnutrition, insecticide-treated nets for protection against malaria, and deworming medicine for worms infestation. It can also be a platform to register children or promote health promoting behaviours such as hand washing.

In many countries, efforts to improve childhood immunization rates have been linked to access to school for children with disabilities, because learners cannot enrol until they are immunized. While enrolment for children with disabilities has increased significantly over the past decade, the global percentage of children with disabilities in school still remains low.

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Emphasis on the inclusion of children with disabilities in educational settings may act as an important incentive for parents of children with disabilities to immunize their children in infancy and childhood. It may also provide an important entry point to reach parents of young children with disabilities. In addition, contact with health professionals through immunization programs may help facilitate the early identification of a child’s disability and help generate referrals to specialists and early childhood development programmes.

The benefits of immunization are increasingly being extended across the life span to include adolescents and adults, providing protection against life-threatening diseases such as influenza, meningitis, and cancers that occur in adulthood. Despite the fact that equal access to health is a right protected under the CRPD, a growing body of research shows that adults with disabilities routinely receive less access or health care, or go without it entirely. As immunization efforts are expanded to reach more adolescents and adults, the routine inclusion of adolescents and adults with disabilities must be considered and pursued.

Key Concerns, Recommendations, and Next Steps

If progress is to be made in ensuring universal immunizations and in improving the health and well-being of children, including children with disabilities, the following must be done:

1. **Efforts should be made to reach caregivers of unimmunized children with disabilities as well as parents with disabilities who themselves may not be aware of immunization efforts in their communities or the need to be immunized.**

   - Campaigns to reach parents of children with disabilities are needed, both through general public health campaigns, through disability-focused groups (DPOs), and NGOs that provide services to children with disabilities, through schools and via the mass media. Targeted efforts, such as talks, pamphlets, information on local DPO and NGO websites help bring a new level of understanding and awareness to these issues.

   - Adults with disabilities have children at rates comparable to their peers without disabilities and often are not reached by immunization campaigns due to a number of factors including inaccessible information or lack of access to facilities. One strategy to reach these parents is through collaboration with local DPOs and NGOs that work on disability issues (e.g. a clinic with a sign language interpreter for the Deaf community; a door-to-door immunization project for children of mothers with physical disabilities). The need for such adaptations are already well understood by the disability community and can be anticipated and planned for.

2. **Efforts must be made to educate health care workers about the importance of immunizing children and adolescents with disabilities.**

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Health care workers often have little or no training on disability issues. It is not unusual for a health care worker to believe, as with some parents and other members of the general public, that a child with a disability is not at risk for catching an infectious disease.

Other health care workers are keenly aware that a child with a disability is at risk; however they worry that the child would react badly to immunization. For example, nurses, doctors, and even public health officials have been reported to refuse to immunize children with epilepsy and spina bifida, because it ‘would make or cause them to have seizures.’ Disability alone is not a counter-indication for immunization. Clear guidelines by UNICEF and associated health experts on both the health benefits of immunization for children with disabilities, as well as discussion of any circumstances where clinicians should refrain from immunizations are needed. Until such guidelines are developed and widely disseminated, some health professionals will continue to hesitate to immunize children with disabilities.

3. There is a need to collect more information and data to better understand the situation of immunization for people with disabilities.

There is a paucity of information available on how many children with disabilities are being reached by routine immunization and immunization campaigns. While there are many on-going systems to monitor and evaluate immunization efforts at the local, country and global level, the existing structures should include indicators related to disability. This would provide much needed data to provide a clear picture of the situation.

Within these data collection efforts, immunization rates for girls and children with disabilities from ethnic and minority communities, as well as from rural communities, should receive additional attention. Studies routinely show these children are less likely to have access to health care than boys or children with disabilities from mainstream and urban communities.

Disability should be incorporated in on-going surveys such as Demographic Health Surveys.

Further studies on the barriers to immunization for children with disabilities (i.e. access and barriers such as stigma) are needed.

Efforts should be made to sensitize national governments and leaders in public health and immunization on gathering data disaggregated by disability, age and sex.

More data is need on what happens to children who have or will acquire impairments as a result of diseases that are preventable through immunization.

4. The messages used to promote immunization efforts should be respectful and disability-friendly.

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47 Ibid.
• Too often, immunization campaigns have used the image of a child with a disability as the example of what parents should most fear. Posters depicting children on crutches or wheelchairs with captions like ‘Don’t let this happen to your child’ or ‘Do you want this tragedy to happen in your home?’ may get people’s attention, but it unnecessarily reinforces negative stereotypes towards persons with disability. There are many ways to encourage parents through positive messages— for example, posters that include images of children with disabilities as part of a group of children, all of whom should be immunized.

• Notably, while children with disabilities often face stigma and prejudice, this is not universally the case. Understanding local attitudes towards children and adults with disabilities is important before starting major immunization effort. For example, in the Ecuadorian community study noted earlier,\(^{48}\) children with disabilities had the same immunization rates as their non-disabled siblings. Resources that would otherwise be devoted to ensuring inclusive immunization efforts can, in this particular community, be devoted elsewhere.

5. **Encourage closer collaboration and consultation between key players working on immunization and the disability community.**

• The expertise and insights of the global disability community, as well as local organizations representing people with disabilities (DPOs), NGOs that provide services to people with disabilities, and parent groups with experience raising children with different types of disabilities, can all be of significant assistance to UNICEF and partners to improve immunization services and provide more accessible and inclusive health services. More specifically:

  • DPOs which are groups led by and for people with disabilities themselves, NGOs that work on behalf of persons with disabilities and parent groups (organizations run by parents of children with disabilities which are often organized around children with specific types of disabilities or based on children with common medical diagnoses) could all provide significant assistance to UNICEF and UNICEF partners by ensuring that:

  ○ Parents of children with disabilities are informed about the need to immunize their child with a disability.
  ○ Parents with disabilities are informed about the need to immunize their children.
  ○ Information is offered in accessible formats and communications do not reinforce negative messages about people with disabilities.

• Children who acquired impairments from diseases that are now preventable by immunizations, cannot be seen as failures in an evolving public health system.

• UNICEF and partner agencies should consider establishing Advisory Boards on Inclusion composed of experts and advocates from the disability community and

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other marginalized groups at local, national, and international levels to advise key partners on immunization projects.

Conclusion

Although more information is needed on the situation of people with disabilities and immunization, there are indications that they are not getting immunized at the same rate as their peers without disabilities primarily due to social and cultural determinants. People with disabilities have the right to survival and the highest attainable standard of health without discrimination on the basis of disability, including immunization. The health and disability agendas should be brought closer together to ensure prevention efforts such as immunization, do not further stigmatize people with disabilities.