

White Paper: Strengthening Inclusion Strategies for Children with Disabilities (CWD) within the context of Care Reform.

Author: Gwendolyn Burchell MBE

ABSTRACT

Building on the research carried out to prepare the *Family Care of Children with Disabilities: Guidance for Frontline Workers in Low- and Middle-Income Countries*, this paper further develops the concept of inclusion described in the Guidance and promotes three pillars of inclusion that may be currently missing in policy making and planning strategies of donors, institutions and State bodies. The author analyses successful practices used throughout the world in order to make detailed recommendations that challenge past and current approaches to inclusive planning and programming.

This paper will address one of the most challenging problems in development work which is commonly referred to as the 'silo mentality'. In this case, this mentality affects how services for typical children are planned and implemented without including the needs of children with disabilities from the first planning step. Strategies are proposed that can help to bridge this gap.

Inclusive program planning is essential if the needs and welfare of all children are to be addressed with equity. Children and youth with disabilities will have equal opportunity to succeed when provided with services and supports that are individualized to meet their needs within the context in which they play, learn, and socialize with other children in their communities. This outcome may be achieved when the key stakeholders in program planning and implementation have access to holistic training that gives them a rounded view of disability and enables them to support all children and families equally, through their improved understanding.

All children deserve to grow up in a family; their need for love and attention is not affected by disability or developmental delay. **When you build a system for children with disabilities, you build a system that works for all children.** When you compartmentalize from the first planning stage, you bring the stigmatization of disability into your work practice.

This paper explores the reasons why a strategic approach to inclusion in care reform is essential, and then follows on to make the case for defining three pillars for successful inclusion policy:

- Guiding Frameworks, which help us to contextualize inclusion
- Implementation, within the context of team development, training, services & standard operating procedures (SOPs)
- Sustainability, in relation to professional development, income generation & economic livelihoods, and advocacy

The paper concludes with a recommendation for a sustainable model or practice, and then responds to three questions that may have particular relevance to a donor agency, based on the arguments put forth in this paper.

The White Paper is based on the author's extensive research into this issue already, through publications listed in the Reference section at the end of this paper, in addition to research carried out for the [*Family Care for Children with Disabilities: Practical Guidance for Frontline Workers in Low & Middle Income Countries*](#). Alongside the theory, the author has over 20 years of practical experience of inclusion in social service development in Azerbaijan, plus consultancy experience with teams in Guatemala, Ukraine, Kenya and Cambodia, to date. This consultancy experience has served to confirm the author's theory about gaps in child welfare reform related to inclusion.

STRATEGIC APPROACH TO INCLUSION POLICY

For inclusion to be successful, I argue that this policy must rest on a number of crucial pillars that need to be adequately developed by stakeholders for inclusion to have a fighting chance of being reached.

This White Paper aims to define and analyze these load-bearing pillars and make key recommendations for donors and implementing organizations so that they can strengthen their inclusive strategies.

I consider the following three questions to be vital to discuss in order to achieve the goal of inclusion and which will be summarized in the final conclusion:

1. Why should donor organisations ensure that inclusion is the starting point in any child welfare reform project or program?
2. Why do projects/programs consider children in separate classifications, rather than as children foremost, some with additional needs?
3. What impact has the COVID-19 pandemic had on all children, making inclusive strategies essential?

The common goal in early childhood is to prepare young children to participate fully in school, community, home, recreation etc. Effective parenting is provided through frequent, warm and responsive interactions, environments that are enriched with not just talking, but language itself, experiential activities and social-emotional learning. This is the ideal.

In the case of children who are affected by family break-up, poverty and disability, their early years may not provide the foundation for optimum development, leading to abandonment by their family, or isolation and exclusion from society. A recent Harvard paper¹ has highlighted biological links between negative experiences in the early years and poor long-term health outcomes. The authors demonstrate clear scientific connections between the environments we create and the experiences we provide for young children and their families which affect not just the developing brain, but also many other physiological functions. Adverse experiences in early childhood are linked to negative outcomes in cardiovascular health, diabetes and mental health. These findings are relevant for public health policy in all countries but those with limited resources may struggle in addressing these issues adequately. External assistance can be invaluable if it is planned and executed with inclusive practices at the core, helping a country to reduce the long-term fiscal impacts of lack in investment in early years.

Optimizing a child's development depends on the society and context that the child lives in. The existing social systems² in Western countries that are in place have been so since the Industrial Revolution changed the nature of capitalism by transforming economies that had been based on agriculture and crafts into economies based on large-scale industry, mechanized manufacturing, and the factory system. This certainly will have contributed towards the stigma and discrimination towards disability and developmental problems due to issues of utility – a person's value being based on their capacity and contribution to economic output. As the world shifts from this industrial age towards the technological age, inclusion itself shifts from a rhetorical objective to one that has real potential to be realized, and within a context that opens up opportunities that are not limited by human physicality. In other countries, religious and political ideologies have driven social policies of the past, seeking to limit individual development because of their goals to serve god or the state, and excluding those that distract from these goals. Capitalism, however, demands free and creative thinkers and approaches which include all members of society, so as to maximize economic gains through participation. The technological age must surely strengthen this as the world moves on from manufacturing as the predominant economic model, and physical labour increasingly becomes replaced by artificial intelligence.

Systemic change relies on external influences that can establish new systems whilst sustaining themselves as old systems die out. This is the crux of deinstitutionalization and the establishment of alternative care strategies. Advocacy can play a part in influencing the systemic change but it must be recognised that most individuals in a political system have no power apart from the position that they are in, and so those systems perpetuate when an issue is low priority, controversial or acting in opposition to political will. Unfortunately, the care of children with

¹ National Scientific Council on the Developing Child, June 2020 – see bibliography for details

² meaning health, education, social security, housing, social services etc.

disabilities is generally considered a low priority by a majority of governments, which serves as a legacy of the ingrained medical model. Therefore, the argument holds that if we, as drivers of inclusion, do not place children with disabilities at the core of our pilot reform projects, we surely cannot expect stakeholder governments to prioritize disability.

Many international NGOs and donor agencies have pledged to support the deinstitutionalization of childcare, with plans that include returning millions of children back to their own or alternative families, and putting in place the prevention services needed to stop the continuing inflow of children to care. In order for this pledge to reach its objectives and contribute towards systemic change for children and families in general, it makes sense that the needs of children with disabilities must be at the heart of all policy and planning – *a system that is designed for the needs of children with disabilities will work for all children but a system that is designed for typical children first, is a system that will continue to exclude those with disabilities.*

Worldwide data corroborates this strategic approach. The 2011 WHO *World Report on Disability* tells us that approximately “15% of the world’s population lives with some form of “disability” and that approximately 5% of children have a disability. We also know from data that children with disabilities are over-represented in institutions:

“Children with disabilities have been disproportionately represented in institutions around the world, presenting substantial concerns about the effect on their development, health, and welfare, their exposure to abuse, and their isolation from their families and communities” p.612, The Lancet, Volume 4, Aug2020

My own research in Azerbaijan during the period 2000-2004 bears out this over-representation. Personally visiting 42 institutions in 2000, followed up in 2004 with repeat visits to 28 of these institutions, I found diagnosed disability ranged from 7.2% to 31% as a share of the numbers of children in care. This must take into account that 20 years ago, State services were chronically under-funded and disability was under- or misdiagnosed. The figures also do not take into account developmental delays, emotional and behavioural problems. These children would have been labelled as ‘stupid, bad or born of prostitutes and drug addicts’, which were common statements given by care staff at that time.

My findings are echoed in another paper, published by the Better Care Network, that also argues for the need to put children with disabilities at the centre of child welfare reform: *“Depending on definitions and data collection methods used, between 14 and 35 per cent of children have disabilities. In Central and Eastern Europe and the Commonwealth of Independent States (CEE/CIS), around one third of children in institutional care have disabilities.”* (P.4 Delap, 2012)

Nevertheless, we can also find the same trend within a highly resourced and developed social service system. Orme J.G et al underline the prevalence of numbers of children with disabilities in care in the US at approximately 25-30% in comparison to the incidence rate of disability worldwide, in their paper on ‘Who is willing to foster children with disabilities?’

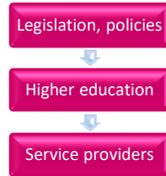
The higher than average number of children with disabilities in care settings strengthens the argument for prioritizing their needs when planning any type of child welfare reform program. Considering that poverty is often quoted as being a key reason for abandoning or placing a child in care, and that poverty and disability are inextricably linked for a variety of reasons, tackling these issues together with an inclusive approach could lead to better long-term outcomes for children, families and care reform.

The following chapters set out the pillars that can be embedded in programming and project financing in order to strengthen inclusion.

PILLARS FOR SUCCESSFUL INCLUSION PROGRAMMES

1. Guiding Frameworks – resolutions & legislation

Historically, the medical model has been the guiding framework for countries that have established institutional systems of care for children with disabilities. Based on the premise that disability equates with sickness or physical defect that can be cured or fixed, this model has permeated the whole system – from terminology used in legislation and policies, to how a country’s higher education curriculums are developed and taught and the subsequent service provision which utilizes these graduates.



In an effort to shift to social and rights-based models of disability, the UN and WHO have been instrumental in putting in place legislative and rights-based frameworks to support this shift from their position of influence.

Since the late 70s, WHO has been promoting the Community-Based Rehabilitation (CBR) model which has evolved from medical approach with a focus on rehabilitation, to a more inclusive and participatory approach often referred to now as CBID – community-based inclusive development. In 1989/90, the UN Convention on the Rights of the Child was mandated, and then followed in 2006 by the UN Convention on the Rights of Persons with Disabilities; these two Conventions have been the driving resolutions behind more inclusive policies.

However, global frameworks need skillful and experienced implementation to be truly inclusive. For example, some detractors comment that CBID programs today seem to have removed all therapy interventions related to rehabilitation, which is concerning in countries which do not have adequate State services for disability. Balancing a child or adult’s needs in their gross motor, fine motor, cognitive, communication, social and self-care skills along with reducing the barriers to participation from a community perspective would surely create a very strong and effective program. Having observed so many parents desperate for a miracle to ‘fix’ their child, neglecting the therapy and rehabilitation needs may lead to disillusionment amongst families, and missed opportunities to encourage their participation in the skills development of their child. It could represent a ‘push’ factor for continuation of residential care.

Goldman et al (p.618/619, *The Lancet*, Vol4, Aug2020) recommend that a system approach combining bottom-up and top-down initiatives is more likely to address all the causes and consequences of institutionalization than either approach individually. In this case, CBR/ID may offer a full and rounded approach to the deinstitutionalization of children with disabilities, as it can address the common problems that lead to institutionalization with a cohesive, bottom-up approach.

An example of good practice of taking inclusion into national frameworks is noted here:

In Jordan, the Higher National Council for Disability³, led and staffed by people with disabilities, is an excellent example of how a country with limited resources is committing itself to ensure that legislation leads to meaningful implementation. This Higher Council is a GONGO (government-owned NGO), autonomous but state-funded. It operates as a policy think-tank, a coordinating & networking body, and implements advocacy and awareness actions, representing all stakeholders. Under new Jordanian disability legislation (2017), they are a technical focal point and will have a unit for M&E. They will be responsible for overseeing accreditation standards and they report directly to the Prime Minister’s office. This ensures that the Council has the power to ensure that legislation is followed, taking into account one of the common problems of the ‘silo mentality’ in implementing legislation.

Most recently, in 2020, two publications which provide a definitive framework for child welfare reform are a series of articles published by *The Lancet*, regarding ‘a child’s right to family’ and the UNGA 2019 Resolution on the Rights of the Child, with a focus on children without parental care. Whilst neither addresses disability and inclusion

³ <http://www.hcd.gov.jo/en>

per se, it is in the implementation of these frameworks that inclusive planning becomes paramount, and which this White Paper will discuss in more detail.

2. Implementation

2.1 Inclusion in the context of Team Development

'Despite all the directives about sharing and caring, best practices etc, it still does come down to the individuals in charge and how well or not that they manage and include the specialist organisations into their planning and implementation'. Edward Carwardine; Director, UNICEF Azerbaijan, 21 October 2019

This challenge is also echoed in the CBR Manual, authored by Dr Thomas M., in which she highlights that the lack of organisational ability and knowledge about disability on the part of community development organisations acts as a major barrier to integration (p.11).

For a program to be highly effective in achieving inclusion, therefore, we need to explore these barriers in more detail. Experience shows that skills, knowledge and practice in child development is a natural precursor to understanding disability when working with any child. It is an essential part of training for any frontline team as well as management team, if inclusion is to be fully understood and realized.

- Lack of awareness and education in how children develop underpins the inability to see all children as children first, all with differing needs, especially those who have experienced challenging early years and institutionalisation
- Lack of awareness and experience with disability at all management levels creates the silo mentality in planning and implementation that characterises much of the deinstitutionalisation programming today

Children follow similar trajectories in their development. Some children who are challenged by a disability may not attain some skills, and others may take longer to develop skills due to processing delays that may, for example, be caused by experiences in early childhood.

In knowing the typical milestones of child development, it becomes easier to identify if a child is delayed and in which skill area/s. One does not have to be a specialist to observe this but it would enhance a team if this capacity exists. Based on current evidence, 43% of children aged under 5 years living in low and middle-income countries face a risk of inability to realize their maximum development capacity (Black et al, 2017). This may seem unbelievably high when considering the average incidence of disability (10-15%), but it takes into account other relevant factors that a team must be familiar with when working on care reform programs.

In summer 2018, UAFA⁴ carried out a small study of typical children aged 0-4 years using the International Guide for Monitoring Child Development⁵. Results showed that 34% of the participating children were developmentally delayed for their age, particularly in the areas of speech and communications. There was no indication that these children had a disability, and they would have been considered by their community to be developing typically. However, the screening process showed areas of delay that indicate the role that environmental factors may play in hindering a child's development.

A much more comprehensive study in the US has demonstrated more cause for concern when working with underprivileged populations. Dr Fernald, a psychologist working for the Centre for Infant Studies at Stanford University has spent her career studying the impact of socio-economic status on communication. One result demonstrates that there is a vast difference in vocabulary between low-income families and middle-income families that can be observed in children from 2-3 years: by age 24 months, there was a 6 month gap between low-income groups in processing skills critical to language development, because they hear far fewer spoken words than children in middle-income groups (estimated 30m less words)⁶. Dr Fernald found that there is a significant difference in vocabulary and language processing skills when parents talked directly to their child, as opposed to when a child mainly overhears speech. This is important to know and understand, and build into programs that focus on early intervention and parenting.

⁴ NGO – United Aid for Azerbaijan

⁵ <https://bernardvanleer.org/ecm-article/2017/international-guide-monitoring-child-development-enabling-individualised-interventions/>

⁶ <https://news.stanford.edu/news/2014/february/fernald-AAAS-children-021414.html>

Adverse Childhood Experiences (ACEs) is a decades-long field of study in early childhood development that is gaining more attention in publications and policy debate. The economic and social costs to families, communities, and society are high if ACEs are not given due consideration in mitigation strategies. Toxic stress from ACEs, potentially traumatic events that occur in early childhood by experiencing violence, abuse, or neglect, witnessing violence in the home or community, can impact brain development and affect abilities in attention, decision-making, learning, and response to stress. Many of the countries that are the focus of child welfare reform have experienced war, economic and political transition and entrenched poverty. These all have an impact on the family and therefore on the child, and it is important that donors and program teams are aware of and are able to plan for this challenge when they are working to reintegrate children to families, or prevent family break-up.

ACEs can be mitigated through creating and sustaining safe, stable, nurturing relationships and environments for all children. Inclusive programs recognize that all children may be affected by these problems and that what might be observed as a disability may be the effect of early childhood neglect, which is a common impact of early placement in residential care: *'Combined, these studies suggest that age 6–24 months constitutes an especially sensitive period for the effects of institutional care..... Children might have a greater capacity for recovery if removed from institutional care in infancy.'* (p.714, Volume 7, *The Lancet*)

A team with limited academic understanding of early childhood development and disability may also be quick to believe institutional staff and Ministries when told that children are too sick to leave residential care, that they require medicalisation which is not affordable to parents. Actually, what may be occurring is that the child is being given medicines because they believe that the child is sick and needs medicines, either to keep the child subdued because of behavioural issues or to manage neurological impairment. This is commonly seen with cerebral palsy and autistic spectrum disorders. In the case of cerebral palsy, there is no evidence that medical treatment will do any more than relax muscles to enable habilitative therapy to be more effective. It is unlikely that institutions in low-income countries would have the budget for complex medical treatment, in any case. In these cases, if a program budget allows, contracting an experienced neurologist and physiotherapist to assess the children would assist a program team in making successful care plans.

We must also take into account the increasing medicalization in some countries of what used to be considered normal in children's behaviour. Once a child has a label, or medical diagnosis, the tendency is for the label to be considered before the child. The identity of the individual is subsumed by the 'defect', and it can become a tool to be used either in defense of a child's need for education or for exclusion. This is an on-going debate in many Western countries where incidence of ADHD, for example, is leading to increasing medicalization within mainstream education, to avoid exclusion and enable a child to 'fit in' (Sluiter MN et al). As donors and program teams tend to look to the West for guidance, these negative trends must also be taken into account.

In 'The Helping Relationship', Professor Hilton Davis outlines his insights into supporting some of the most disadvantaged children and families, including those with disabilities and developmental delays, and found that Western models tend to rely too highly on professional staff (meaning therapists and other allied services) but do not take caring and listening into account, leading to more stress within the family. In country contexts where care reforms are taking place, policy-making and strategic approaches are often influenced by Western specialists and consultants who draw on their own experiences in high resource contexts. Prof. Davis is highlighting some of the drawbacks of the Western models and presenting an opportunity for care reform to evolve more inclusively, with the following recommendations. A strong community-based program takes these into account:

- Western models cannot be copy/pasted and understanding of 'child-centred' may be challenging in country contexts where children are 'seen but not heard'
- Role of Active Listening – this is a key skill in helping parents to better understand their children and their role in supporting them
- Parent relationship is crucial to improving outcomes for children

Inclusion has to start before education, and so it makes sense that a program starts at the beginning of a child's life and considers all the variables and components needed when planning a strategy, starting from when the challenges leading to exclusion start - at birth.

The purpose of outlining key examples of child development information is that successful inclusion needs a well-trained team who understand child development. Alongside improving awareness of disability, policies that support inclusion, funding streams and other components of an integrated system, a team that has skills and

experience in child development and disability/special need/developmental delay is one that is more likely to achieve real progress. The baseline is that all children are children first and foremost.

2.2 Inclusion in the context of Training

Three of the key messages in the second Paper from *The Lancet* (p.606) are:

- National child protection systems should be grounded in a continuum of care that prioritises the role of families
- Local programmes should address the drivers of institutionalisation and address the specific needs of each child and family
- Donors and volunteers should redirect their funding and efforts to community-based and family-based programmes

As explained in section 2.1, this Paper presents the argument that inclusion (in the context of care reform) is embedded in the knowledge and practice of child development. The continuum of care cannot differentiate between children if it is to be inclusive, therefore transferable skills are essential in ensuring that any systems and programmes are effective for all children.

Transferable skills represent a broad and integrated set of trainings and experience that can be used across all services or systems that aims to be inclusive of children with disabilities, and particularly relevant to low resource settings.

In most developing country contexts, the lack of locally qualified specialists has not been adequately addressed, with mainly ad hoc trainings provided by (mainly English-speaking) specialists travelling internationally, sharing skills with non-profit organizations or State personnel. Long term strategic planning of skills development may not be given adequate attention.

Skills training requires more than a couple of weeks of course time – it requires supervision to help a new trainee put the skills into practice, make mistakes and improve. It requires an intrinsic understanding of terminology used, an understanding that may not even exist in translation. Is there any evidence that the popular ToT model – Training of Trainers– has much impact? Experience shows that many of those who participate in ToTs often change their position, whether they are working for State or NGO, due respectively to administrative change or lack of funding. The training is then lost, and cannot do much beyond raise awareness.

A more sustainable approach could be to invest in staff of NGOs to build a long-term resource that can work across the continuum of care and contribute to the country's professional development as their experience and skills grow. With a thorough foundation in skills and practice, the staff can then support the inclusive planning of all services related to child protection and deinstitutionalisation, both within the NGO and in partnership with State bodies.

For example:

Within existing models, a 'special needs' teacher is trained to work with a group of children with different needs and how to accommodate all these needs within a class, whereas a typical teacher (in teacher-centred models) is trained to provide a set curriculum of information that a child must learn, usually in order to pass exams that they need to enter higher education or to gain employment. When inclusion is built into teacher training based on child-centred methods of learning (inquiry, choice, creativity, participation), those teaching skills are then applicable to all children, and education is delivered using a variety of different tools and learning styles. Current understandings of inclusion tend to focus on placing a child with disabilities in the classroom (closer to the definition of integration than inclusion), rather than focusing on inclusive teaching and its individualised approach to learning.

A skilled team that is respected locally because of their training and experience is one that can help systems and professionals begin to develop and shift away from the medical model and exclusion. In the context of this paper, I refer to this set of skills as '*transferable skills*'.

An example that may suit donor interests in systemic development is the CHED Foundation Course⁷ – Childhood Health, Education and Social Development. This course has been developed in partnership

⁷ <http://ched.az/en/home/>

between UAFA and the Centre for Child & Human Development at Georgetown University⁸. It is grounded in the idea that the silo mentality starts at the higher education level when students specialize in different sectors. This course combines the broad learning in health, education and social development needed to create a new cadre of *child development specialists* that can work in each sector. It is designed to be financially sustainable, meaning the fees will cover the costs of the course. Some donor funding has been invested to cover the establishment costs. The Faculty is comprised of foreign-qualified specialists residing in Azerbaijan working alongside local specialists to provide a course that is quality controlled by GU. It combines theory and practical supervision across 3-6 months of direct access to the Faculty, with certificates provided by GU. The course is taught in Azerbaijani which enables non-english speakers to have access to a high-quality certification course without having to leave the country. This model can be applied in many other low-resource countries and is a step in the direction of building the new professions needed to change minds, attitudes and practices towards child development and disability.

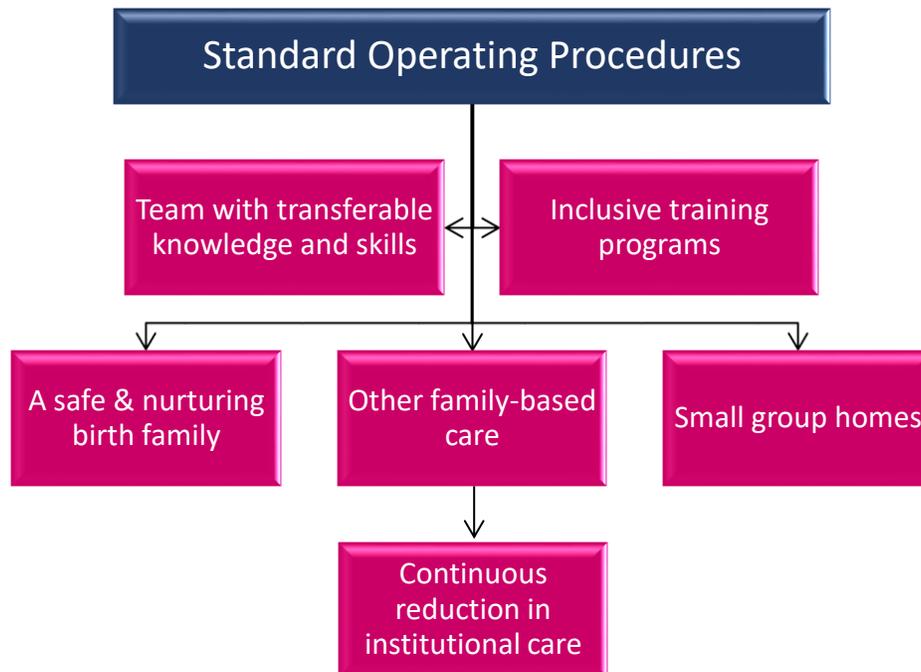
Over time, as this cadre of students matures, their skills and experience will filter into the policy, planning and provision of ECD services, leading to generational change and, crucially, inclusion.

⁸ <https://gucchd.georgetown.edu/>

2.3 Inclusion in the context of Services & SOPs

Standard Operating Procedures that are designed for all children, alongside a well-trained team that has transferable skills, will create the conditions necessary for projects and programs to become fully inclusive.

Using the Continuum of Care (p.617, Vol 4, Lancet) as a baseline, the following diagram⁹ depicts how inclusion can be streamlined:



Typical services include:

A safe & nurturing birth family

- Family strengthening through partnering with case managers
- Early Intervention (0-3 years), working in partnership with families

Other family-based care

- Kinship, foster, kafala, adoption, reunification with birth family – for all children

Small group homes

- Contentious, but still provided in high-resource countries, though with high levels of care and family participation, and including respite services for families of children with complex needs

Institutional care

- Progressively eliminated through reducing numbers, reunification and alternative families

Cross-cutting: inclusive education, respite care, day-care

⁹ Please note, the role of small group homes in alternative care reform is contentious because there is evidence to show that many perpetuate institutionalization of children on a smaller scale. The US Government's [Advancing Protection and Care for Children in Adversity: A U.S. Government Strategy for International Assistance](#) aims to enable children to live in family care and does not support the use of small group homes.

Each of these services typically involves case managers, service providers and CBR workers who need the *transferable skills* in order to have a 'toolbox' for each setting, meaning that even in low resource contexts, each trained individual has something to offer a child/family member/carer that may prevent care placement or isolation at home. [*Family Care Guidance for Frontline Workers in Low- and Middle-Income Countries*](#) (Salmon E. & Burchell G) was written exactly for this purpose and is a valuable tool that can be used as is, or adapted/translated for different countries.

A practical example of how an organisation can become more inclusive can be seen with Children in Family's (CIF) ABLE project, in Cambodia. The NGO specializes in foster care with the ABLE project being a separate project for fostering children with disabilities. During a visit in March 2020, it was observed that there was a clear distinction between those who worked with typical children's cases and those who worked with children with disabilities. The teams sat in separate rooms; the Management staff and non-ABLE case managers had no knowledge and experience in disability, meaning that they just automatically referred children to ABLE. There were two Operations Manuals – a separate one for each foster service. This separation by project was also reflected in OSCaR, an open source the case management and record keeping system used to manage cases. Following this feedback, the organisation reviewed their operations and streamlined processes to build a fully inclusive approach.

Foster care is a generic service for children, and a proportion of the children coming through foster care may have some kind of developmental, emotional or behavioural issue, even if not a diagnosed or visible disability¹⁰. If systems are the same for any child, and those with disabilities receive the extra services they need, such as physical rehabilitation from the ABLE specialist staff, CIF would be a truly inclusive foster care organisation. The whole team would benefit from appropriate training in child development and disability, alongside their case management training, and this would also support the inclusion of the specialist ABLE staff to the rest of the team – thereby avoiding the silo mentality in which services for typical children are planned and implemented without including the needs of children with disabilities from the first planning step.

It must be noted that these organisational divisions can be an outcome of funding, when one project receives more donor attention than another. However, an organisation that thinks inclusively will be able to strategically align their internal planning and operational practices. Compartmentalizing from the first planning stage only serves to perpetuate the stigmatization of disability in a work practice.

Inclusive education can play a crucial role in successful destigmatisation as well as deinstitutionalisation, because exclusion from mainstream education at kindergarten age is a strong driver for placement in care. Yet pilots are often poorly designed due to lack of detailed understanding, or follow the copy/paste approach that tries to take Western practices and implant them into different contexts which are not ready to accept such drastic steps. For better outcomes, inclusive education should focus on how children are taught – all children. It is the teaching that must change, rather than children with disabilities being included as a token gesture. Mainstream schools should aim to accommodate all children regardless of their gender, ethnicity, physical, intellectual, social, emotional, linguistic or other conditions. In low-income countries, the allied services are rarely available to be able to follow a western-style Individual Education Plan (the standard tool for inclusion that is advocated in care reform), yet CBR programs may have more success in including children with disabilities into mainstream education because they focus on community participation and wider skills sharing (Azimova, 2019), building the conceptual understanding from the bottom-up.

Moldova has had significant success in piloting inclusive education, with reviews stating that 'IE systems and preparing households to receive children home was critical to deinstitutionalisation of the child care system and successful reintegration of children' (Partnerships for Every Child, p.10). This was achieved through a comprehensive systems change approach; that is, putting in place all the elements of the system needed to prevent children from being placed in care, to reintegrating those already in care with a thorough assessment of needs and available support, then filling in the gaps. From joint inter-ministerial trainings, to public awareness, to individual education plans for each child, the whole system was addressed and primed for change. Overcoming the barriers to inclusion and supporting each child and family to ensure successful inclusion is a strongly recommended course of action for reintegration and reunification of children with disabilities.

¹⁰ <https://pediatrics.aappublications.org/content/106/5/1145>

In terms of addressing stigma and discrimination, inclusive pre-school is often a missed opportunity by some organisations. This is an age when

- children play together easily,
- parents of typical children are less likely to be concerned about the effects on their own child of mixing with children with disabilities and
- pre-school teachers are more adaptable to child-centred, inclusive pedagogy with some training and support.

This paper forecasts that in the future a major driver for inclusive education will be the technological change that is taking place globally, helping economies (and associated education systems) to shift from a manufacturing model of capitalism to one that will naturally be more inclusive because it is based on thinking outside of the box, that does not require physical coordination and strength, and where assistive devices are built into the change.

3. Sustainability

Child welfare reform is a long-term commitment; it takes multiple funding cycles, many mistakes and continuous advocacy to achieve significant impact. To ensure some consistency in voices and practices, donors could invest resources in supporting NGOs to become sustainable resources for their country, so that they can be present over the long-term to influence development as it ebbs and flows. NGOs can be a catalyst in the following areas for sustainable development in care reform.

3.1 Professional development

Where training does achieve some stability is in private practice or at University level.

The ENOTHE program¹¹ to establish the Occupational Therapy (OT) profession in higher education has had great success in many low-income countries around the world, and has attained high skills retention because of the higher education status of this program, and long-term commitment to each country. The Republic of Georgia has been graduating internationally-recognised OTs at the Tbilisi State University for 15 years as a result of partnership with ENOTHE, and most graduates are employed in private, non-State and State services, as well as contributing back to the on-going development of new graduates. This was funded by the EU/Erasmus program.

Universities can be one of the key drivers in changing how society approaches disability and attitudes, through their curriculum and research output. The graduates are the ones who go into the labour force as doctors, teachers, psychologists and so on. Their learning and practice can either influence change or maintain the status quo. Whilst an NGO may not be in any position to collaborate with a university, they do have a role to play in advocacy. A strong and specialised NGO can be a catalyst to curriculum reform if they have managed to build the reputation that convinces the academic bodies to listen.

3.2 Income generation & Economic livelihoods

Sustainability of the NGO is vital, especially if they are replacing the State in case management and essential services. Dependency on grants and donations is not a practical strategy; it does not give the team the stability they need to focus on service development, rather creating a project-to-project mentality. If funding stops, and all case management ends, this will have long-term consequences for the children and families concerned, and create a push-situation, sending children back to institutions.

Two alternative strategies are proposed. First, lobbying for the State to contract with NGOs as consultants and service providers, and, second, generating independent sources of income through (social) enterprise development. Combining both strategies would be ideal – governments are prone to slashing social budgets in times of austerity or crisis, with services for disability too often being decimated¹². State contracting can allow for the NGO to generate a basic level of income to maintain its teams, whilst attracting other funds to tackle new projects and strengthen professional development. There are various models in practice, particularly in post-Soviet countries such as Russia, Azerbaijan and Ukraine.

One organization that has followed the social enterprise route is called Shonaquip¹³, based in South Africa. This organization is a women-led wheelchair business which makes and sells the chairs whilst working with children and parents to promote inclusion. Running a social enterprise enables an autonomy which being totally grant-funded does not. For any NGO thinking of their long-term survival, mentoring can help them to develop a social enterprise strategy that suits their skills base and resources.

This social enterprise strategy can also integrate programs addressing livelihoods of the families that the organisation is working with to prevent family break-up. Any initiative that aims to reintegrate or keep children at home with their family ideally needs to address all the issues that lead to exclusion or abandonment. Poverty, alongside disability, is one of the main reasons for most families in low-income countries, and these two issues are inextricably linked. Successful childcare reform should be embedded within economic development programs to provide a holistic approach.

¹¹ <https://enothe.eu/home/what-is-enothe-2/>

¹² <https://www.theguardian.com/books/2019/jun/18/crippled-austerity-demonisation-disabled-people-frances-ryan-review>

¹³ <https://shonaquip.co.za/>

We should also take into account that most families do not abandon their children because of disability, meaning that those who do are likely affected by multiple social problems. These problems can be addressed within a wider-ranging socio-economic development program, rather than addressed in isolation.

A very good example of this multi-layered approach was established in Bangladesh since 1972 by BRAC¹⁴, the world's largest NGO. Underpinned by social enterprise, which provides over 80% of its funding, it follows a development approach at village level that combines economic development, education, public health and women's empowerment to create a holistic approach to poverty reduction. It has worked so well that the country's economic growth surpassed Pakistan's by 2018¹⁵. BRAC can be a good model to support inclusion and deinstitutionalization.

The COVID-19 pandemic has exposed situations, such as in Kenya where 20,000 children were sent home from private institutions, leaving behind mostly those with disabilities, and where large proportions of populations are experiencing increased poverty, now is the time to establish a new approach to embedding care of the most vulnerable children into effective national poverty reduction strategies.

3.3 Advocacy

In order to strengthen all of the above, advocacy is a vital component of the work of any specialist organization and all team members would benefit from participating in advocacy training. Advocacy in the case of child welfare reform, given the investment that a donor may make to an organization, should be politically neutral. Their cause is to improve outcomes for children, and this cannot be achieved if an organization positions itself publicly against a government or political individual. Advocating against a proposed policy can be more acceptable when the argument is given in terms of the potential impact on a child, and it is more effective if backed up with original research from the particular country. Strengthening research capacity, or partnering with research organisations, will help to build a program's or NGO's reputation and influence on positive reforms for children.

3.4 Summary of a sustainable model/practice (recommendation)

This is a checklist that summarises Sections 2 and 3, and can act as a guide for donors, policy-makers and international agencies to strengthen their inclusion objectives when working with partners in the field of child care reform. Organizations should:

1. Be driven by the cause, with track record of action/implementation that demonstrates this focus,
2. Strive for sustainability based on State funding/in-kind support and social enterprise;
3. Use donor funding to pilot an approach, but not fund it in perpetuity;
4. Be service-based, as opposed to project-based;
5. Mainstream disability throughout the organisation – team expertise, training programs, standard operating procedures, etc.;
6. Actively involve parents of children with disabilities in the organisation using participatory approaches;
7. Play an advocacy role with government structures for policy based on practice;
8. Develop services for prevention as well as for reunification and reintegration, demonstrating skills relevant to both;
9. Make decisions based on field experience, not at headquarters and
10. Develop a staff with a range of professions in child development and disability, not just managers.

¹⁴ <http://www.brac.net/>

¹⁵ <https://www.brookings.edu/opinions/why-is-bangladesh-booming/>

CONCLUSION

Inclusion is built on a complex set of variables but is at the core of democratic ideology. It is a potent force for improving equal opportunities for all. The COVID-19 pandemic has created a unique situation by confining people all around the world to their homes, preventing them from socializing, working or engaging in usual life activities. This may give more of us an insight into what life is like for people with disabilities every day when the barriers to inclusion are not brought down.

Three questions were posed in the introduction and will now be answered:

1. Why should donor organisations ensure that inclusion is the starting point in any child welfare reform project or program?

As this paper establishes, disability is not a clear-cut issue and there is much evidence of developmental delay due to socio-economic circumstances as well as institutionalization that can negatively impact a child's growth and skills development. A team which follows inclusive approaches to child development and service provision is a team that has solutions for all children.

2. Why do projects/programs consider children in separate classifications, rather than as children foremost, some with additional needs?

This may be due to lack of experience, knowledge and practice in child development and disability. When a team has a background in working with children with disabilities, they understand that all children are different and have individual needs. Putting disability first leads to programs that work for all children.

3. What impact may the COVID-19 pandemic have had on all children, making inclusive strategies essential?

COVID-19 has led to increased adverse childhood experiences in some children, with less play and socialization, and less opportunity for communications development. For those children with parents who understand this and have done their best to mitigate this impact, the effects will likely be negligible. For children, those with and without disabilities, who are confined to institutions or who are experiencing neglect or abuse at home, the effects are likely to be magnified, leading to reduced outcomes for those children as they grow up.

This paper has been written in an effort to provide some insight to inclusion and best practices with the aim to support organisations around the world to streamline their inclusion strategies.

Author:
Gwendolyn Burchell MBE
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REFERENCES

- Resolution on the Rights of the Child*, adopted by the UN General Assembly on 18 December 2019
- Salmon, E. & Burchell, G. – [Family Care Guidance for Frontline Workers in Low and Middle Income Countries](#), 2018; USAID/World Learning
- Van Ijzendoorn, MH et al
Institutionalisation and deinstitutionalisation of children 1: a systematic and integrative review of evidence regarding effects on development
The Lancet Volume 3, pages 703-720, August 2020
- Goldman, P.S et al
Institutionalisation and Deinstitutionalisation of children 2: policy and practice recommendations for global, national and local actors
The Lancet Volume 4, pages 606-633 , August 2020
- CSIE (Centre for Studies on Inclusive Education) (2018) “*What is inclusion?*” Retrieved from <http://www.csie.org.uk/inclusion/what.shtml>
- Schuelka, M.J. (2018) *Implementing Inclusive Education*. K4D Helpdesk Report. Brighton, UK: Institute of Development Studies
- Delap, E; EveryChild
Enabling Reform: Why Supporting Children with Disabilities must be at the heart of successful child care reform – 2012
- Orme, JG, Cherry, DJ & Krcek, TE
Who is willing to foster children with disabilities? (2013); Journal of Public Child Welfare. 7:5, p.566-585
- Dr Thomas, M and Thomas, MJ
Manual for CBR Planners, 2003; published by www.dcidj.org
- Black, M.M., Walker, S.P., Fernald, L.C., Andersen, C.T., DiGirolamo, A.M., Lu, C. et al.
Early childhood development coming of age: science through the life course. The Lancet 389: 77–90
Lancet Early Childhood Development Series Steering Committee için. (2017).
- Feldman et al, various papers on infant studies: <https://web.stanford.edu/group/langlearninglab/cgi-bin/publications.php>
- Prof. H. Davis: *The Helping Relationship: Understanding Partnerships*; published by Interconnections, 2007 - http://www.tacinterconnections.com/images/stories/journal-pdfs/The_Helping_Relationship_No_6.pdf
- Azimova, S & Burchell, G - *Successful inclusion in Azerbaijan: outcomes of UAFA's education-based intervention services*; May 2019
- Partnerships for EveryChild: Final Report – *Children in Moldova are Cared for in Safe and Secure Families project* - 2017
- Paediatrics Journal: *Developmental Issues for Young Children in Foster Care*; Vol, 106, Issue 5, 01 Nov 2000
- Sluiter, MN., Wienen, AW., Thoutenhoofd, ED., Doornenbal JM. – *Teachers' role and attitudes concerning ADHD medication: A qualitative analysis*; 04 July 2019, Psychology in the Schools, Wiley Periodicals
<https://doi.org/10.1002/pits.22270>