DEINSTITUTIONALIZATION FOR CHILDREN WITH DISABILITIES: TECHNICAL GUIDANCE FOR UNICEF'S ENGAGEMENT IN NATIONAL REFORM EFFORTS

HELEN JONES 2019

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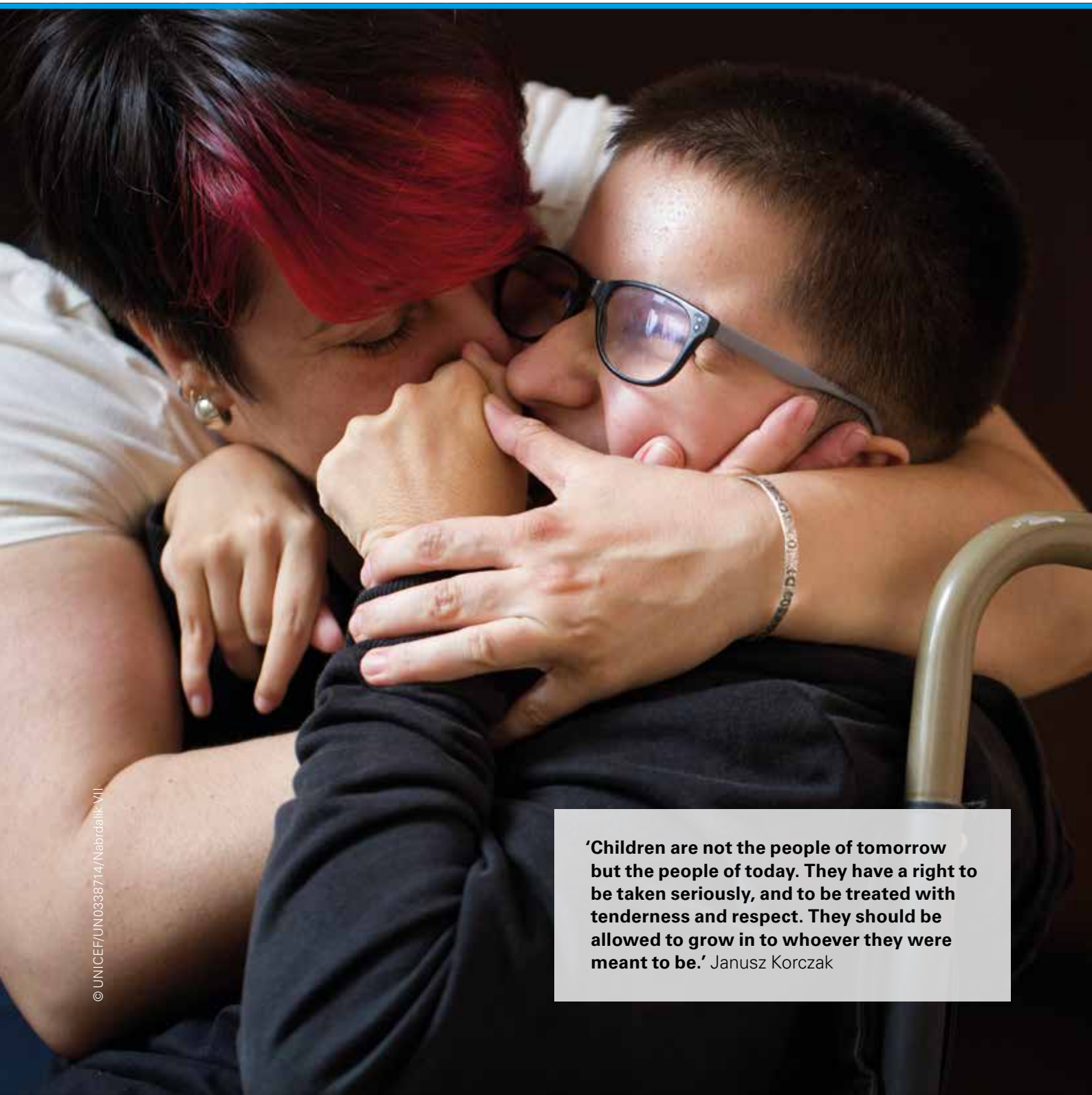

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'Children are not the people of tomorrow but the people of today. They have a right to be taken seriously, and to be treated with tenderness and respect. They should be allowed to grow in to whoever they were meant to be.' Janusz Korczak

Acknowledgements

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Thanks are also due to the individuals and organisations who gave their time to ensure that my visits were wide-ranging and informative. Particular thanks go to the parents who allowed me to observe the therapeutic work being undertaken with their children in early intervention centres and those who shared the challenges and joys of raising a child with a disability.

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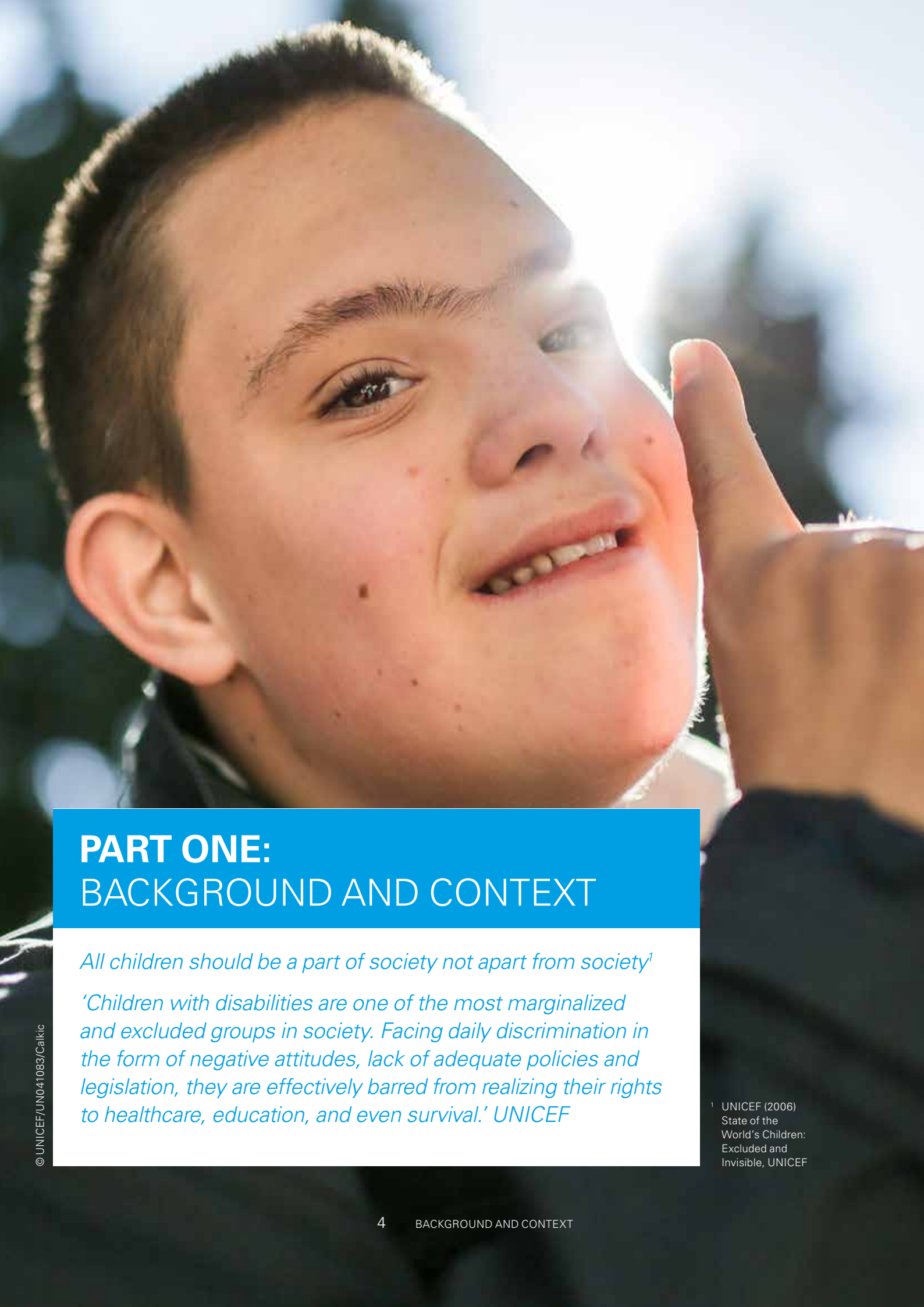

PART ONE:
BACKGROUND AND CONTEXT

All children should be a part of society not apart from society[1]

'Children with disabilities are one of the most marginalized and excluded groups in society. Facing daily discrimination in the form of negative attitudes, lack of adequate policies and legislation, they are effectively barred from realizing their rights to healthcare, education, and even survival.' UNICEF

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[1] UNICEF (2006) State of the World's Children: Excluded and Invisible, UNICEF

Purpose

1. The technical guidance has been commissioned by the UNICEF Eastern Europe and Central Asia Regional Office (ECARO) to enable UNICEF Country Offices (COs) to advocate and support particular programmes and projects related to the deinstitutionalization of children with disabilities through:

- Promoting better decision-making among policy makers and child welfare professionals in the region regarding deinstitutionalization of children with disabilities;
- Supporting governments to understand the need for such work and to plan, monitor, evaluate and sustain the reforms, as well as linking these reforms to broader disability-inclusive changes across sectors and making a contribution to social justice;
- Increasing political will, passion and vision for the development of a child care system to address the range of needs of children, stimulating preventive work to reduce overall numbers placed away from home, and promoting family-based alternatives for the majority of children in the care system.

2. The guidance therefore:

- Examines the institutions currently caring for these children, as well as the services needed to provide and support effective family-based alternatives, community support systems and mainstream universal services, both to deinstitutionalize and prevent institutionalization
- Enables UNICEF Country Offices to stimulate these reforms by describing the key elements of the deinstitutionalization process, including prevention, and setting out the characteristics of high- quality care for children, including those with disabilities
- Provides practical tools for their implementation, monitoring and sustainability

Definitions

3. The definition of disability used in this guidance is *'Persons 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'*.[2]

4. The term 'deinstitutionalization' refers both to the return of children to the community from institutional settings and the prevention of entry to institutions. When the definition of institutional care includes boarding schools and some small group homes, it is clear that numbers of children entering institutions is increasing in a number of countries in the ECARO region. It is therefore essential that as much attention is paid to the prevention of children, particularly young children, entering institutions as to enabling them to return to live in families and communities.

The United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

'Children with disabilities in the ECA Region are almost 17 times more likely to be institutionalized than other children.' [3]

5. The international conventions are clear on the rights of children and adults with disabilities to the same protections as others, articulating both their rights and, for children, best interests as the primary consideration. The key sources of these rights are the UN Declaration of Human Rights[4], the UN Convention on the Rights of the Child (UNCRC)[5] and the UN Convention on the Rights of People with Disabilities (UNCRPD)[6]

[2] UN Convention on the Rights of Persons with Disabilities (UNCRPD) Article 1

[3] UNICEF (2018) ROAR 2017: Europe and Central Asia Regional Office Annual Report. (UNICEF)

[4] United Nations Declaration of Human Rights (General Assembly resolution 217 A) (1948)

[5] United Nations Convention on the Rights of the Child (1989) (UNCRC)

[6] UNCRPD op.cit.

6. The key Articles of the UNCRC supporting the deinstitutionalization of disabled children are set out in the box below:

The CRC states that "for the full and harmonious development of his or her personality" the child should "grow up in a family environment, in an atmosphere of happiness and love and understanding". In addition, it outlines a range of children's rights that, taken together, suggest that most children should live with and be cared for by their birth families **(Articles 9 and 7)**. It is the primary responsibility of parents to raise their children and it is the responsibility of the state to support parents in order that they can fulfil that responsibility **(Article18)**. Children have the right to protection from harm and abuse **(Article 19)**, to an education **(Article 28)** and to adequate healthcare **(Article 24)** but they simultaneously have the right to be raised by their family. Where the family cannot provide the care they need, despite the provision of adequate support by the state, the child has the right to substitute family care **(Article 20)**. Children with intellectual or physical disabilities have a right to live in "conditions which ensure dignity, promote self- reliance and facilitate the child's active participation in the community" **(Article 23)**.

7. Specific obligations to support the right of people with disabilities to live in the community are set out in Article 19 of the CRPD:

Article 7 – Children with disabilities

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 19 – Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

A rights-based framework and the needs and capacities of children with disabilities

8. The UNCRC, the UNCRPD and the UN Guidelines for the Alternative Care of Children all recognise that the ideal setting for a child to develop and thrive in, and for people with disabilities to fulfil their potential and participate as full citizens, is within a family that provides a nurturing and loving atmosphere, or, when necessary, within a community- based care system which is suitable to meet their individual needs and develop and promote their capacities. Settings for children with disabilities must recognise and support individuality and provide opportunities for the exercise of choice and agency in line with Article 7 of the CRPD. In addition to the human rights and social justice arguments, there is a strong economic case for choosing family- and community-based care over institutions. The cost of providing family- and community-based care is often less expensive and the social return is much higher although in the

shorter term there are significant transition costs which must be factored into the budgets.

9. After decades of evidence-based advocacy and policy dialogue, many governments **have** led reforms to close or transform large-scale institutions and replace them with community and family- based alternative care services and put in place family support services to prevent children from being unnecessarily separated from their families. Throughout the countries in the ECARO, significant progress has been made in terms of the development of new child and family services, although continued investment and momentum is required to ensure the reforms are irreversible and no child is left behind. Children with disabilities are particularly vulnerable to institutionalization because of negative societal attitudes and the range and complexity of community- based services that are needed. Institutional settings are particularly damaging to children with disabilities because they are unable to offer the relationship-based care needed to maximise their potential.

10. At the same time, the varying paces at which different services have been developed, and their uneven availability across time and location, have hindered the reforms and sometimes created unintended consequences. Not all initiatives have given sufficient attention to the complex challenges of deinstitutionalizing children with disabilities or recognised the range of services which need to be in place to make community-based care a successful alternative to institutionalization.

11. The ECARO Regional Disability-inclusive Strategy[7] has already identified a number of the issues developed in this guidance and is supporting initiatives to take them forward. It should therefore be used in conjunction with this technical guidance. The Disability- inclusive Strategy is broad-view guidance encompassing all needs and support by all sectors and stakeholders while this guidance provides more details on how specifically to support deinstitutionalization of children with disabilities.

Children with disabilities and a child-first approach

12. The recognition of the importance of family life for **all** children comes from the wealth of evidence from theories of attachment and child development, as well as more recent findings from neuroscience, that relationships are the fuel of human growth and development. These theories are equally applicable to children with disabilities - they are children first and inclusion is a fundamental human right. For most children, parents and families are the best source of these nurturing relationships and public policy should be directed to ensuring that they are well-resourced to provide them. It is not possible to replicate these relationships within any institutional setting as individualised relationships and attachments cannot be developed and sustained.

13. However, the statistics on institutionalization rates of children with disabilities in the region suggest that they have not been included in relevant legislation, policies and practice for supporting children's development, including deinstitutionalization, on an equal basis with their peers, and to do so now requires a period of dedicated attention and action in order for them to catch up and access the family and community-based services that other children have as a right. As well as mainstream universal services however, some will require access to a range of targeted and specialist services (as per the three-tier approach explained in the regional disability strategy), in order for their developmental needs to be met and the barriers to their inclusion overcome.

14. Considering the needs of children with disabilities within the context of what all children need is essential to mitigating against the poverty of expectation which blights the potential of children with disabilities in the Region and beyond.

[7] UNICEF. Draft Regional Disability-Inclusive Strategy 2018-21. UNICEF 2017

The development of the guidance

15. This guidance has been developed from a number of sources:

- background reading of research and evidence-based practices, with specific reference to children with disabilities and other specific learning difficulties and developmental delays;
- the use of theoretical models such as Bronfenbrenner's eco-systemic approach, the Framework for the Assessment of Children in Need and their Families, the social model of disability and implementation science which are particularly relevant to the purpose of the guidance, as they situate the planning and implementation of the deinstitutionalization reform in a multisystemic context (institutional, community and societal);
- study visits to three countries in the ECA region which are at different stages in their deinstitutionalization journeys - Kyrgyzstan, Belarus and Macedonia - visiting a range of institutional and community-based provision for children with disabilities including NGOs and government departments; and
- Reports and analyses undertaken in countries in the ECA Region which provided a major tool for informing policy dialogue and child-focused policy advocacy including lessons learned from both the barriers and successful models

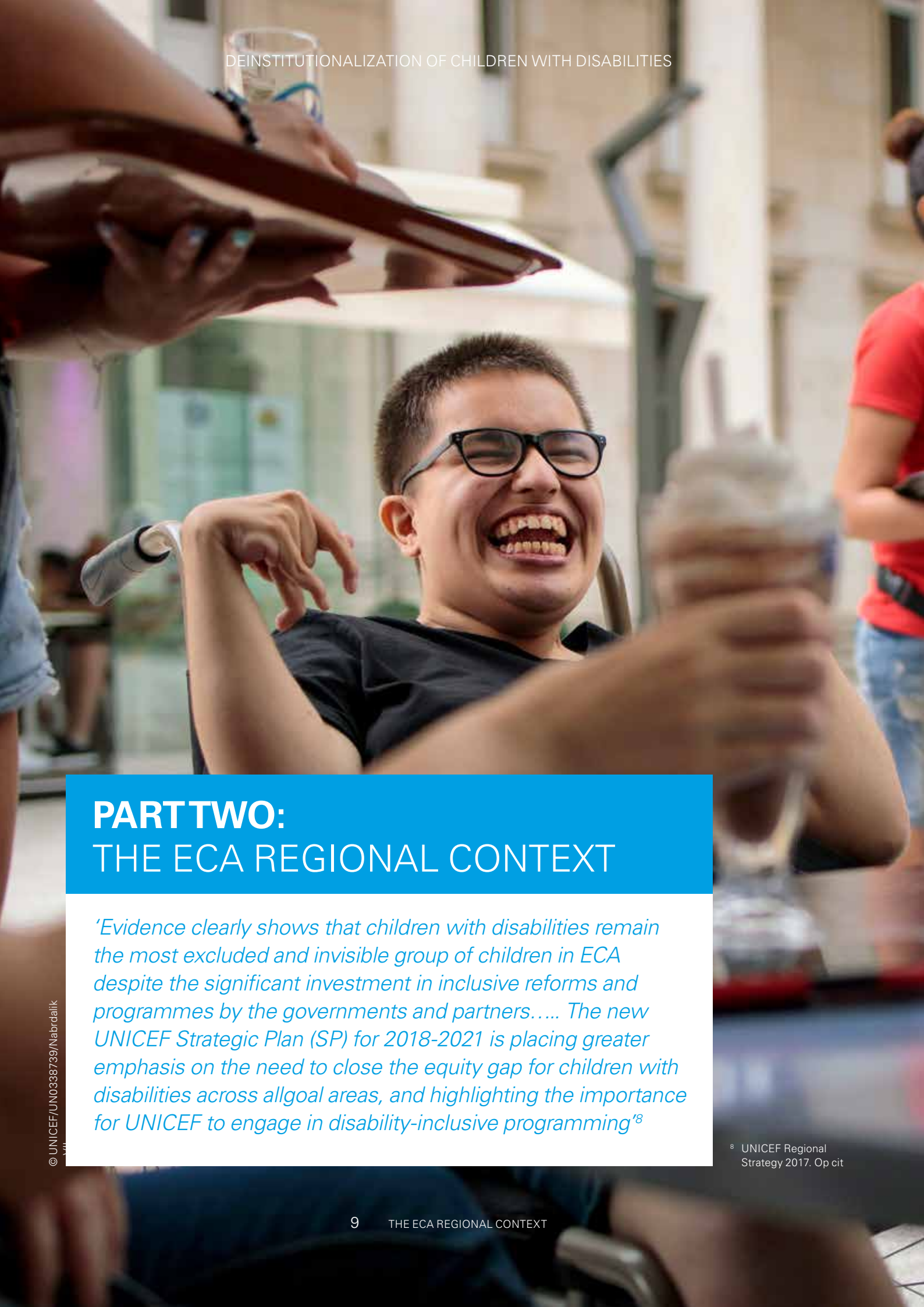
16. The guidance summarises the key drivers for institutionalization; uses evidence from theory and practice to articulate the developmental needs of all children, including those with disabilities; describes the characteristics of settings which are able to meet those needs and the wider support services to which children and their parents and carers will need access. Finally, it proposes a set of core elements of a change process and a set of resources to deliver the deinstitutionalization of children with disabilities.

17. The approach taken in the guidance is to move away from arguments about definitions and merits or otherwise of alternatives to institutional care such as small group homes or family-type care towards an approach which considers the capacity of any provision along the continuum, from care in birth families to specialist residential care services, to meet the developmental needs of all children and children with disabilities. In particular it focuses on the capacity to promote their functioning and empowerment and facilitate access to mainstream services.

18. It is written in a way which is intended to enable individual countries in the region to benchmark themselves against the elements which need to be in place with the help of the tools provided in the Appendices and those available from UNICEF and other sources.

Summary

- The guidance sets out to improve decision-making about the deinstitutionalization of children with disabilities among policy makers and child welfare professionals in the region. In addition, the guidance provides practical tools for the implementation, monitoring and sustainability of the reforms
- It sets the context for the reforms clearly within a rights-based framework centred on States' responsibilities set out in the UNCRC and the UNCRPD to ensure that children with disabilities benefit from family-based care in the same way as their non-disabled peers. This underpins the 'child-first' approach to disability
- Many governments **have** led reforms to close or transform large-scale institutions and replace them with community and family- based alternative care services as well as putting in place prevention services from their families. Not all initiatives, however, have given sufficient attention to the complex challenges of deinstitutionalizing children with disabilities or recognised the range of services which need to be in place to support family and community-based care
- The statistics on institutionalization rates of children with disabilities in the region suggest that they have not been included in relevant legislation, policies and practice for supporting children's development, including deinstitutionalization, on an equal basis with their peers, and to do so now requires a period of dedicated attention and action in order for them to catch up



PART TWO:
THE ECA REGIONAL CONTEXT

'Evidence clearly shows that children with disabilities remain the most excluded and invisible group of children in ECA despite the significant investment in inclusive reforms and programmes by the governments and partners….. The new UNICEF Strategic Plan (SP) for 2018-2021 is placing greater emphasis on the need to close the equity gap for children with disabilities across allgoal areas, and highlighting the importance for UNICEF to engage in disability-inclusive programming'[8]

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[8] UNICEF Regional Strategy 2017. Op cit

Factors which impact on the capacity to de-institutionalize

19. The Region comprises 21 countries in which there are five times the global average number of children living in some form of residential care. The total estimate is 5.1 million children with disabilities in the Region with only 1.5 million formally registered. In addition, countries in the region are at very different stages of the deinstitutionalization journey and, while many countries have seen significant reductions in the numbers of children with disabilities in institutions, others have seen slower progress and even increases in numbers, including significant increases in the number of children in boarding schools.

20. In spite of progress made across the region there remains a lack of consistency or coherence of approach and countries struggle with going to scale and maintaining reforms. There is a view that 'it will all happen in time' without targeted effort.

21. The varying paces at which different services have been developed, and their uneven availability across time and location, have also hindered the reforms and sometimes created unintended consequences. There is an increasing concern amongst child care professionals in some of the countries of the region that an emphasis on small group homes (SGHs) during transition may contribute to re-institutionalization or trans- institutionalization rather than provide a bridge to community re-integration and genuine inclusion.

22. The key messages on the general deinstitutionalization process, barriers and opportunities are already well documented:

- Too great a focus on closing institutions, too little focus on investing in community- based services
- Regional disparities in the availability of community-based services;
- Too little attention to the financing and sustainability of newly introduced services;
- Too little focus on preventing institutionalization and particularly the implications of institutionalizing very young children with disabilities
- Lack of coordination with inclusive health and education reforms
- Lack of understanding of the drivers of institutionalization and the need for a cross-sectoral approach to address them
- Lack of attention to changing social norms and the attitudes of the public and professionals
- Insufficient focus on the needs of very young children and their parents

23. Yet the existing knowledge and evidence has failed to have a significant impact on de- institutionalization rates of children with disabilities. It is important therefore to start with an understanding of the particular factors underpinning this failure, which may have similarities but important differences to the factors for institutionalization of non-disabled children, in order to address them.

24. Understanding these issues is the precursor to considering the climate and context for deinstitutionalization of children with disabilities - how committed and ready are all the parts of the systems to address the major changes required of them? How can they be made ready?

25. Another key element in this strategic and systemic approach is assessing the suitability of settings for children with disabilities. A key and consistent finding from visits to settings/provision for children with disabilities in the three countries was a warehousing approach to care which was as true in many day care settings as in residential/ institutional settings and in some foster care. Therefore, identifying some quality markers and criteria for understanding and identifying suitability across sectors and provision is an essential part of this work.

26. Last but by no means least is the very challenging issue of managing transitions from institutional care, where resources are scarce and there are very different views about what constitutes appropriate community-based provision. For these reasons a key approach taken in this guidance as highlighted earlier is to focus on identifying and meeting the child's individual needs and providing quality indicators for suitability of provision, rather than focusing on particular forms of provision. As the Poraka NGO for people with disabilities in Macedonia pointed out in a discussion: *'It's not what type of building but what goes on inside it that matters.'*

27. It is not possible to address these issues in a piecemeal way because of the complex interrelationships between different services and systems. While factors may vary in their weight and relevance across countries in the region, the factors set out below are consistently likely to play a role in driving institutionalization in the region. Part Four provides some practical approaches to addressing these issues systemically.

The factors impacting on institutionalization in the region

28. **Poor planning and silo working:** Where progress is slow or in reverse it is too frequently related to poor planning and co-ordination between Ministries and national, regional and local services in developing appropriate alternative provision. This impacts both on the capacity to move children from institutions to family- based care and on the capacity to maintain children with disabilities within their birth or wider families in the community.

29. **Poverty:** is a major driver in many countries in the region. Many countries are relatively low -income countries but for families who have a child with a disability the amounts paid in allowances to families, including foster families, are rarely sufficient to cover the significant additional costs of caring for a child with disability. These may be child-related costs such as the need for additional heating, medicines, special clothing and food, aids and breakages as well as reduced income from at least one parent being unable to work, largely due to the lack of education provision available to the children and a lack of support to families, including respite care and personal assistance.

30. **Lack of community-based services:** children with disabilities require access to a range of universal, targeted and specialist services in order to minimise the impact of their disability on their functioning. Without such services parents feel that they cannot provide a level of appropriate care themselves to keep their child at home. Such services are at different stages of development across the region and need to be mapped as part of the deinstitutionalization project development. They include:

- Well-informed and supportive medical staff, in the neonatal period as well as at stages of later diagnosis
- ICF-CY assessments and classifications
- Early diagnosis and intervention centres
- Specialist resources to support sensory-impaired children
- Aids and adaptations in the home and environment
- Speech and language therapists
- Occupational and physio therapists
- Access to inclusive education and early years provision as well as appropriate special education available locally
- Specialist /specialised communication tools
- Parenting support

31. **Education:** Lack of access to appropriate local on an equal basis with peers is a major factor for parents in placing their child in an institution or more commonly for sensory impaired children, a boarding school. Truly inclusive schools were rare, particularly at secondary level though great efforts were being made in many places. However, the lack of supports and services to successfully adapt the learning environment to individual children with a wide-range of disabilities hampered efforts. This was particularly true for parents of children with sensory disabilities where the lack of access to appropriate braille or sign language led parents to feel they felt that their children needed 'specialists' who would only be available in a 'specialist' setting. This view was reinforced by the specialists themselves who actively sought to maintain separate provision.

32. In Kyrgyzstan, many children with hearing impairments attended the specialist boarding school as day pupils some distance away from the country capital because of a lack of provision in the city. However, the suggestion to the school Principal that the development of a local day school in the capital would avoid the need for long daily journeys to an already overcrowded school was met with the response that, on the contrary, the school needed to expand as only this specialist provision was suitable.

33. **Lack of effective social work and case management:** A lack of an appropriately qualified social work profession is hampering change across the region as it is not possible to provide effective help to families across the early intervention and child protection spectrum. Effective social work is an essential resource for vulnerable families, regardless of the cause of the vulnerability. Families struggling to come to terms with the implications of having a child with a disability need access to counselling and practical support to navigate the different systems and services which will be involved with their child, if they are to feel empowered and enabled to care for the child at home. Some children with disabilities will be born into families where the adults have their own difficulties, such as drug, alcohol or mental health problems. Without effective social work interventions, the child is more likely to be institutionalized for child protection reasons. The availability of institutions, baby homes and boarding schools provides an all too easy solution for under-trained and under-resourced professionals and a consistent view across professionals and institutions in the three countries visited was that it was the children with disabilities whose parents had their own difficulties who were most likely to be in institutions.

34. **Other workforce issues:** as well as a lack of social work resources, in many countries there is also a lack of key therapeutic interventions for children with disabilities such as speech and language therapists, occupational therapists and physiotherapists available at local level which drives parents to get specialist help for their children through the institutions. Most countries in the region lack even training/qualification programmes for such specialists, magnifying the problem. Donor funding needs to be diverted from buildings and expensive equipment into resourcing effective professional and therapeutic practice and relationship-building activity.

35. **Difficulties in managing behaviour:** There is a consistent lack of specialist parenting programmes for children with disabilities, leaving parents struggling with knowing how to respond appropriately to what can be experienced as challenging behaviour. The lack of understanding and tolerance in communities of these issues, combined with (often) single mothers' anxieties about teenage children bigger than them, too often led to institutionalization in adolescence and a consequent transition to adult institutions. The well-documented high breakdown rate of marriages and relationships of couples who have a child with a disability exacerbates this issue as many of the parents are single mothers struggling to manage their child with a disability, siblings and work. Parenting programmes are widely available elsewhere, benefit all parents and are not costly, compared to the cost of institutionalization but may need to have additional elements for a specific disability, such as appropriate responding to children with ASD.

36. **The poverty of expectation:** Poverty of expectation is a consistent and striking characteristic of the lives of children with disabilities and blights the lives of these children across the ECA Region (and more widely). It affects all of the children, but those with intellectual disabilities in particular. It is linked to the fixed categorisation system (see below) which reinforces the perception that the children will not be able to make any progress in their development with the consequence that little thought is given to providing the quality of care described in Part Five. At a special boarding school in Kyrgyzstan, the children were not allowed to study beyond 9th grade and had an adapted curriculum even for 9th grade. There was neither an expectation nor a practical possibility for them to achieve what their non-disabled peers might achieve.

37. **The categorisation system for disability:** In many countries in the region access to resources is gained through a system/process which gives a fixed category to the child's disability for the long term which it is difficult to change in the future, reduces access to resources and is diagnosis/condition rather than functionality based. Thus, all children with particular syndromes or conditions receive the same category, with little individual assessment or expectation of future progress in development. It is particularly dangerous in countries where institutionalization is a social protection entitlement.

38. **Public and professional stereotypes of disability:** It is clear that public and media attitudes to disability have a huge impact on rates of institutionalization and capacity to de-institutionalize. The effect of decades of keeping children and adults with disabilities out of sight,

behind walls and bars in many instances, is that people are not used to seeing people with disabilities in their communities. Myths and stereotypes abound about the nature of people's difficulties, its heritability and therefore the impact on marriageability of siblings, which leads parents to conceal their child with a disability in an institution. The media therefore have a major role to play in any deinstitutionalization plan. The general public do not see many children or adults with disabilities in functional roles in public so that negative attitudes and attributions remain too often unchanged and indeed reinforced. In addition, it was evident during the country visits that pre-, peri- and post- natal staff tended to retain very negative views about disability and its impact, which are communicated to parents.

39. **Lack of purposeful work:** In the institutions and baby homes visited as part of the assignment there was no evidence of purposeful work being undertaken to support child development, early learning and language skills. This is linked to both professional attitudes and lack of training. Children were being warehoused in environments that offered little stimulation from adults or purposeful work linked to individualised goals for the child, in spite of the presence of many adults. The impact of the failure to stimulate and develop the skills and agency of the children was to make it much less likely that they can be placed in or return to a family, and thus they graduate to the next stage of institutional care. Improvements to the physical state of buildings have not been matched with improvements to what goes on inside them although the impact of the latter is far greater. One recently renovated institution in Kyrgyzstan had new communal toilets offering no privacy to the children.

40. **Current workforce in institutions and local economy resistance:** many institutions and boarding schools remain important employers in poor local economies. While many support deinstitutionalization in principle, it is clear that people are fearful of change which may involve loss of jobs and harm to the local economy. The European study on de- institutionalization and community living (related mainly to adults) identified that *'Closing a large institution could have a major impact on local employment patterns if it is the only or main local employer. Building community accommodation for disabled people in the same communities in order to offer replacement work might not be a sensible option. Residents of the institution may come from other parts of the country and may wish to return to their local community. Local economic development considerations will need to be taken into account.'*[9]

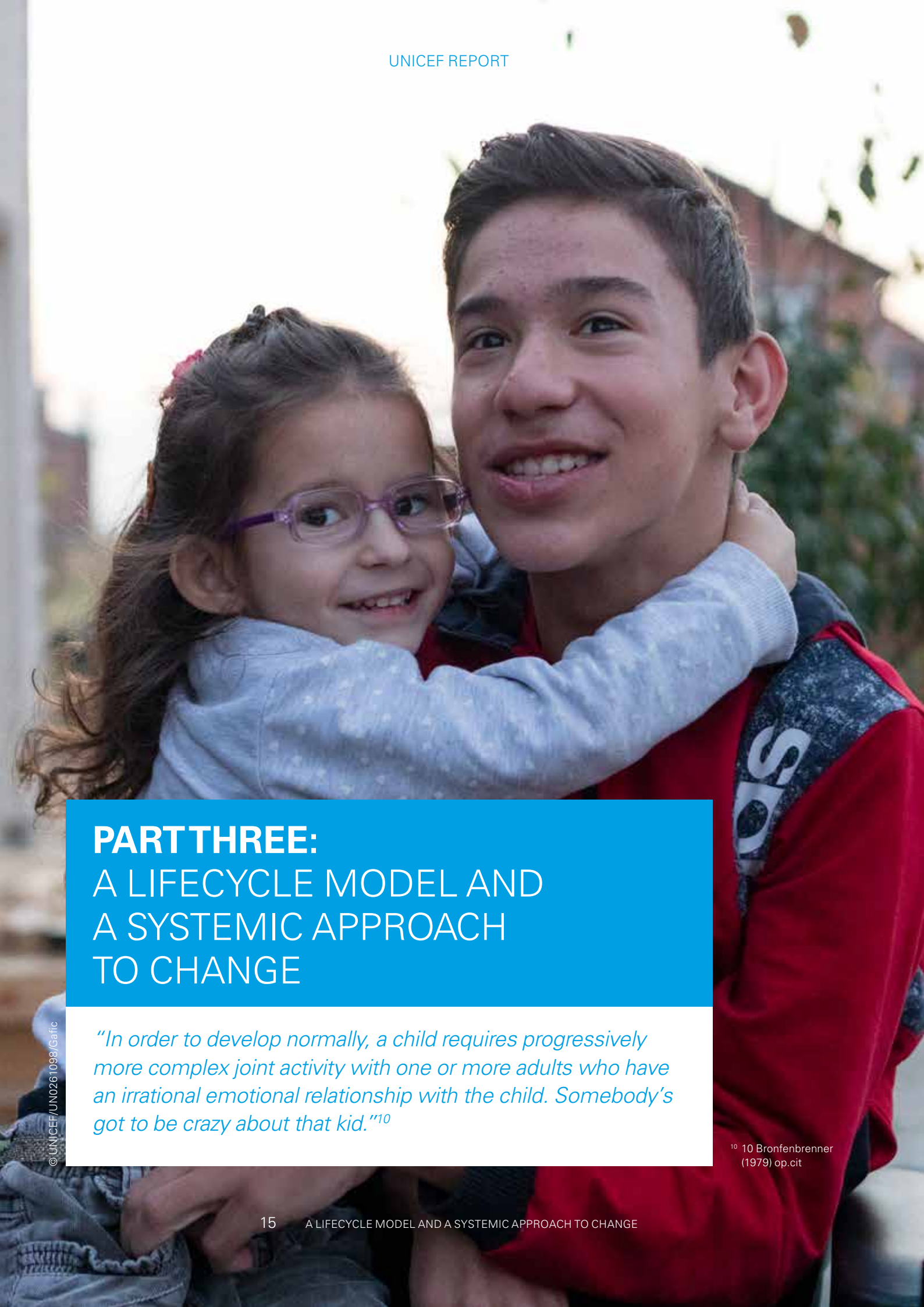
41. **Public policies around the use of institutional settings:** Entry criteria and assessment processes for institutions can impact on the entry rates, based on a poor understanding of the developmental needs of children. In Belarus the Government allows, but does not approve of, entry to boarding schools from the age of 4 and children with sensory impairments such as sight and hearing loss are particularly vulnerable to such placements at young ages. There is little understanding that potential gains from such a specialist service at a young age will be offset by the trauma and loss of attachment figures for the child.

42. **Abandonment:** There is a prevailing discourse among Government Ministries and professionals of 'abandonment' and 'refusal to take responsibility' in the context of parents putting their children in institutions. But across the three countries visited and corroborated in other reports, the consistent messages from parents and those working with them are about their desperate desire to keep their children, but they feel prevented from doing so by lack of money and appropriate local services and the negative attitudes of professionals. It is a view which must be challenged as it pushes 'blame' for institutionalization away from those responsible on to vulnerable parents.

[9] Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 1: Executive Summary. Canterbury: Tizard Centre, University of Kent.

Summary

- There are an estimated 5.1 million children with disabilities in the Region with only 1.5 million formally registered. In some countries, a fall in the number of children in institutions has been matched by an increase in the numbers of children in other types of residential care including boarding schools
- A wide-range of factors influence rates of institutionalization and de- institutionalization, including poverty, silo working, lack of community-based services, including education and social work, professional attitudes to disability and poverty of expectation for children with disabilities
- The creation of family and community-based services must include the development of new professions and practice and measures of assessing quality which focus on promoting functioning



PART THREE:
A LIFECYCLE MODEL AND A SYSTEMIC APPROACH TO CHANGE

"In order to develop normally, a child requires progressively more complex joint activity with one or more adults who have an irrational emotional relationship with the child. Somebody's got to be crazy about that kid."[10]

[10] 10 Bronfenbrenner (1979) op.cit

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43. Although the commission for this guidance has a very practical focus (see Purpose above), it is important to articulate the concepts and theories which have been used to analyse and interpret the issues on the ground and which have informed the development of some of the tools provided in the text and Appendices. This comprises both an ages and stages lifecycle model to understanding children's needs and a systemic approach to delivering change.

44. It is clear that the deinstitutionalization of children with disabilities is a complex, multifactorial process and a systemic model has therefore been chosen to provide a framework for articulating the different elements of the systems and services surrounding children with disabilities and an understanding of how they should work together to deliver the changes necessary to support complex reform. This addresses the common problem with implementing change in which issues are addressed separately and often sequentially rather than understanding the positive and negative systemic relationships between the issues. The Bronfenbrenner eco-systemic model has been used because it provides a framework which links individual child development with the systems surrounding him or her, with a focus on the need to link the different systems towards the same goals.[11]

45. An understanding of child development is key to taking a lifecycle approach and identifying key milestones and supporting positive transitions which can be particularly challenging for children with disabilities. This developmental model is used in conjunction with a framework for understanding and meeting children's individual developmental needs developed in the UK[12] in order to translate the theory into a practice tool to enable those in contact with the child to identify and support key developmental milestones. Other relevant concepts are drawn from attachment theory[13], resilience theory,[14] Bandura's social learning theory [15], the dignities and capabilities framework and from recent developments in neuroscience.[16]

General theories about child development

46. Development is a highly interactive process, and life outcomes are not determined solely by genes. The environment in which the child develops before and soon after birth provides powerful experiences that chemically modify certain genes in ways that then define how much and when they are expressed. Thus, while genetic factors exert potent influences on human development, environmental factors have the ability to alter family inheritance. For example, most children are born with the capacity to learn to control impulses, focus attention, and retain information in memory which are key milestones for successful adulthood, but their experiences as early as the first year of life lay a foundation for how well these and other executive function skills develop.[17]

'Healthy development depends on the quality and reliability of the young child's relationships with the important people in his or her life, both within and without the family. Even the development of the child's brain architecture depends on the establishment of these relationships"[18]

47. While many aspects of brain function, including emotional development, do depend on some key early experiences, they continue to develop well into adolescence and early adulthood. So, although the basic principle that "earlier is better than later" generally applies, the window of opportunity for most domains of development remains open far beyond age 3, and human beings remain capable of learning ways to "work around" earlier impacts well into the adult years. However, because of the developmental challenges and environmental

[11] Bronfenbrenner, U. (1979). The ecology of human development. Cambridge, MA: Harvard University Press

[12] Department of Health; Department for Education and Employment; Home Office. (2000). Framework for the Assessment of Children in Need and their Families. London, The Stationery Office

[13] Bowlby, J. (1958), The nature of the child's tie to his mother. International Journal of Psycho- Analysis, XXXIX, 1-23.

[14] Masten, A. Ordinary Magic: Resilience in Development. (2014) The Guilford Press 2014

[15] Bandura, A. (1977). Social learning theory. Englewood Cliffs, NJ: Prentice Hall.

[16] www.developingchild.harvard.edu Accessed 25.1.19

[17] Center on the Developing Child at Harvard University (2016). 8 Things to Remember about Child Development. Retrieved from www.developingchild.harvard.edu. Accessed 8.12.18

[18] Center on the Developing Child at Harvard University (2009) Young children develop in the context of

barriers faced by some children with disabilities, the early years remain an extremely critical window for maximising development and must be prioritised in the deinstitutionalization strategy. 'Serve and return' provides an important concept in this context.[19]

Growth-promoting relationships are based on the child's continuous give-and-take ("serve and return" interaction) with a human partner who provides what nothing else in the world can offer – experiences that are individualized to the child's unique personality style; that build on his or her own interests, capabilities, and initiative; that shape the child's self-awareness; and that stimulate the growth of his or her heart and mind'

48. It is this growth-promoting experience of individualised relationships which is so lacking in institutions and makes the environment fundamentally unsuited to raising children. The persistent absence of 'serve and return' interaction acts as a double threat to healthy development: not only does the brain not receive the positive stimulation it needs, but the body's stress response is activated, flooding the developing brain with potentially harmful stress hormones. Research has shown that multiple early stresses can lead to developmental delay which for children with disabilities compounds their disadvantage[20].

49. The idea of an individualised relationship is at the heart of attachment theory.[21] The experiences that the child has each day- being engaged in everyday tasks, having opportunities to exercise choice, develop their curiosity- provide opportunities for repetitive learning in a natural way and the quality of everyday carers in promoting these interactions is therefore key.

50. The capacity to adapt and thrive despite adversity develops through the interaction of supportive relationships, biological systems, and gene expression. Despite the widespread yet erroneous belief that people need only draw upon some heroic strength of character, science now tells us that it is the reliable presence of at least one supportive relationship and multiple opportunities for developing effective coping skills that are the essential building blocks for strengthening the capacity to do well in the face of significant adversity.

51. This capacity to do well in the face of adversity is described by Ann Masten of the University of Minnesota as the 'ordinary magic'. She shows that *"Resilience does not come from rare and special qualities, but from the everyday magic of ordinary human resources in the minds, brains and bodies of ordinary children, in their families and relationships, and in their communities."*[22]

52. Most relevant for this technical guidance is her finding that *'The study of resilience has had transformative effects on the guiding frameworks for interventions and policies designed to help children at risk for academic and behavioural problems. Deficit models are being replaced by more balanced models that include assets, strengths, and protective factors along with risks, problems, and vulnerabilities. It turns out that* ***many of the most strategic ways to prevent and ameliorate problems in development may be to promote competence and success****, which is also far more appealing as an objective to parents and the public than programs focused on reducing problems')*[23] (Guidance author's emphasis)

53. Bandura's Social Learning Theory that behaviour is learned from the environment through the process of observational learning is helpful in highlighting the impact of a segregated environment on learning. If children with disabilities are grouped together only with other children with disabilities, they will only learn and copy the behaviours they see around them, thus again limiting opportunities to develop positive functioning skills.

[19] https://developingchild.harvard.edu/science/key-concepts/serve-and-return/ Accessed 10.12.18

[20] Center on the Developing Child (2007). The Impact of Early Adversity on Child Development (In Brief). Retrieved from Retrieved from www.developingchild.harvard.edu. 3.1.19

[21] Bowlby, J. (1958), The nature of the child's tie to his mother. International Journal of Psycho- Analysis, XXXIX, 1-23.

[22] Masten, A. (2014) op cit

[23] S. Masten, Ann & Coatsworth, J. (1998). The Development of Competence in Favorable and Unfavorable Environments: Lessons from Research on Successful Children. The American psychologist. 53. 205-20.10.1037/0003-066X.53.2.205

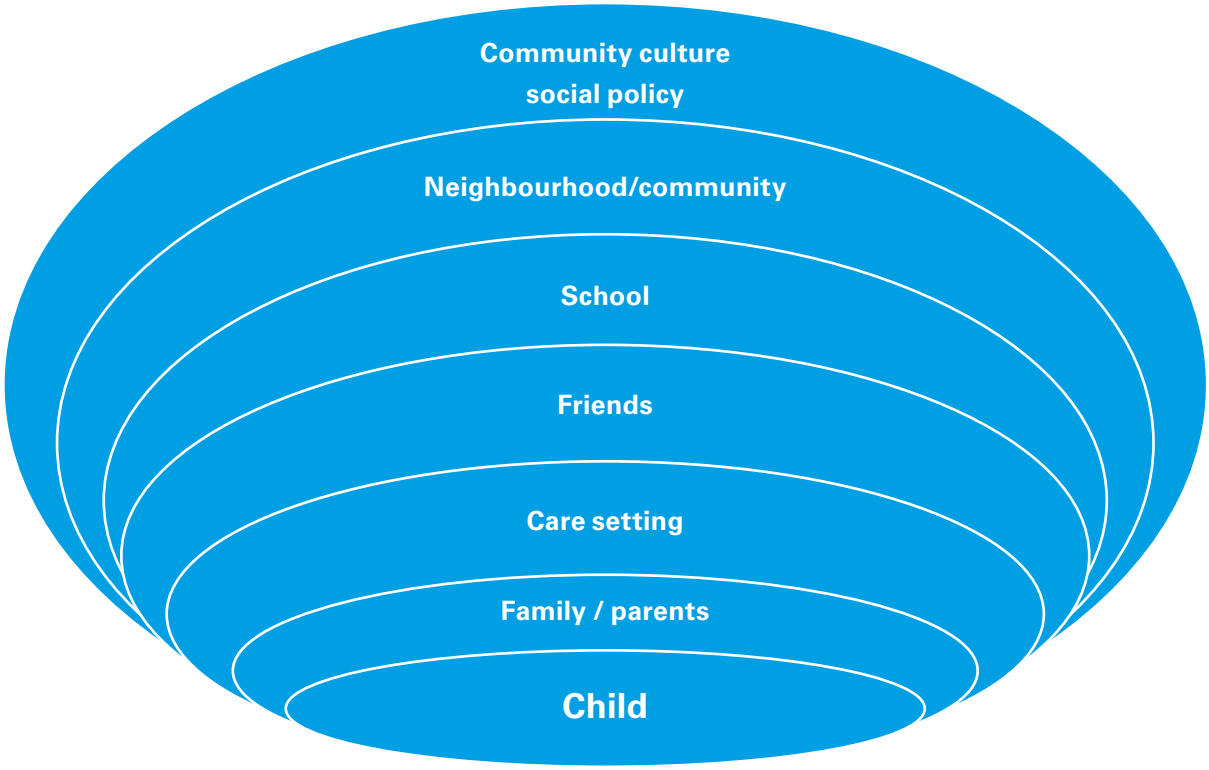
The role of environment in development

54. The Bronfenbrenner ecological systems approach is particularly helpful when examining the relationship between the different factors at play in child development. Bronfenbrenner stressed the importance of studying a child in the context of multiple environments, also known as ecological systems, in the attempt to understand his or her development. These are the factors which impact on the quality of children's daily lives and experiences and the way in which the multiple systems in which the child functions need to work together coherently towards common goals.

55. A child typically finds him or herself simultaneously involved in different ecosystems, starting in the most intimate home environment, moving outward to the larger pre-school and school system within the local neighbourhood and community and then into the systems which are society and culture. Each of these systems and subsystems interact with and influence each other in every aspect of the child's life.

56. In different contexts however, there are different drivers and challenges for reforms for children with disabilities- hence the importance of each country undertaking its own analysis.

Figure 1: Bronfenbrenner's Ecological model[24]



[24] Bronfenbrenner, U. (1990). Discovering what families do. In Rebuilding the Nest: A New Commitment to the American Family. Family Service America

Developmental approaches and disability

57. Bronfenbrenner's theory emphasises how a person's biological characteristics interact with environmental forces to shape development. What is much less well understood is how this applies to children with disabilities. The suggestion that it is the interaction of many processes over time and contexts which determine development may be helpful for children with disabilities as it allows for many ways of intervening when seeking to improve their life situation and developmental well- being.

58. Traditional approaches to disability have focused on making the disabled child more 'typical'. While Bronfenbrenner did not specifically address disability, systemic models support and enable a broader approach to development that is not about 'normal' or 'typical' but about broader goals of function, engagement and participation in life, building on the strengths and skills of the individual and emphasising the importance of environmental factors and barriers in influencing the impact of a disability on a child.[25]

59. The ICF-CY offers an important developmental perspective on disability as it provides a classification of functioning and disability that is applicable to all people, irrespective of health and learning conditions, and in all physical, social and cultural contexts. It concerns everyone's functioning and disability, and was not designed, nor should be used, to label persons with disabilities as a separate social group. By shifting the focus from health condition to functioning, it places all health conditions on an equal footing, allowing them to be compared using a common metric. Domain definitions are worded in neutral language, wherever possible, so that the classification can be used to record both the positive and negative aspects of functioning and disability. Further, it clarifies that it is not possible to infer capacity for participation in everyday life from diagnosis alone.

60. **The Nurturing Care Framework**[26] is another helpful framework, informed by Bronfenbrenner's model, which describes how a whole-of-government and a whole-of- society approach can promote nurturing care for young children. It outlines guiding principles, strategic actions, and ways of monitoring progress many of which are relevant to this guidance and underpins UNICEF's approach to its work in the early years.

Common approaches to understanding and assessing development

61. In the UK in the late 1990s a framework for assessing children's developmental needs was developed to support social work practice which provides a systematic way of analysing, understanding and recording what is happening to children and young people within their families and the wider context of the community in which they live.

62. The development phase of the Framework for the Assessment of Children in Need and their Families[27] (The Assessment Framework) identified that effective collaborative work between staff of different disciplines and agencies assessing children in need and their families requires a common language to understand the needs of children, shared values about what is in children's best interests and a joint commitment to improving their outcomes. The Assessment Framework provides that common language, based on explicit values about children, knowledge about what children need to ensure their successful development, and the factors in their lives, including parental capacity and environmental factors which may positively or negatively influence their upbringing.

[25] Skelton, H. and Rosenbaum, P. Disability and child development: Integrating the Concepts. [online] available at www.canchild.ca/resources Accessed 29.12.2018

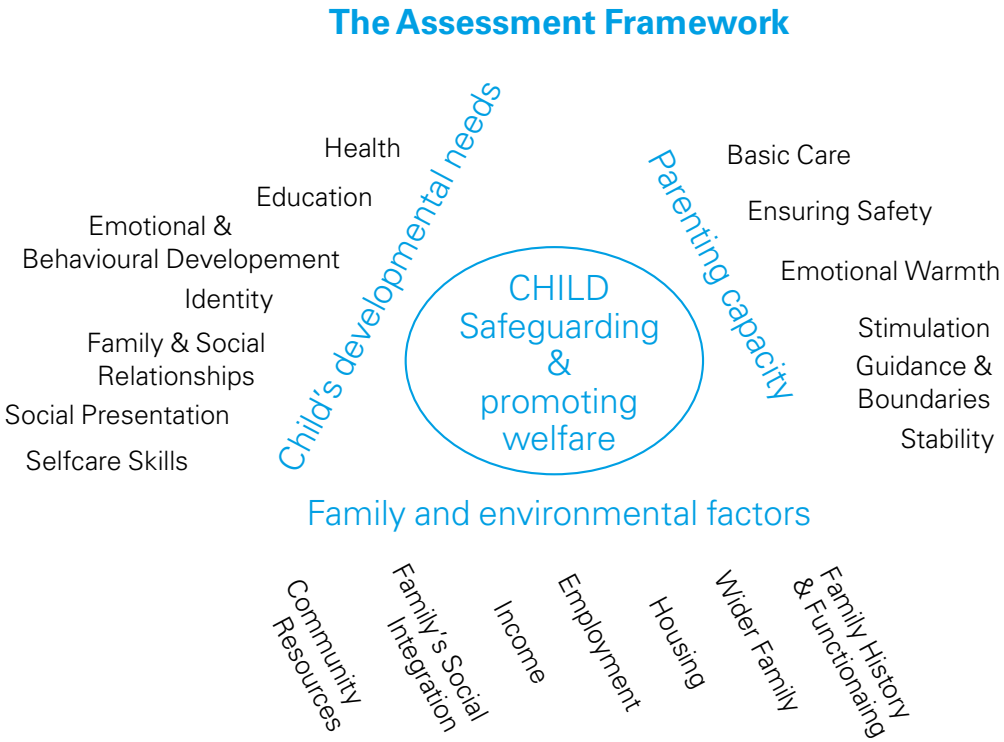
[26] https://nurturing-care.org/resources/nurturing-care-framework-toolkit/ Accessed 15.03.2019

[27] Department of Health et al. (2000) Op.cit

63. In particular, the common language of child development enables professional in the team around the child to articulate the actions and goals of their service which will contribute to improving outcomes for the child.This common language increases the likelihood of parents and children experiencing consistency of messages between professionals and themselves about what will be important for children's wellbeing and healthy development. Within the law in England and Wales, children with disabilities are defined as children in need of services in recognition of the additional support needed to put them on an equal playing field with other children. This common language has enabled the framework to be used not only in a social protection context but by a range of other services and professionals such as health, education and the police.

64. The Assessment Framework was the outcome of substantial research and consultation about the core developmental needs of children and is set out below:

Figure 2: The Assessment Framework



65. An additional concept which is highly relevant to all children but for children with disabilities in particular, because it is so rarely regarded as applicable to them, is that of agency. It is about children's sense of choice and control in their own lives and in a recent PhD study of (non-disabled) Romanian care leavers[28] was shown to have greater weight than type of placement in determining outcomes as young adults. This adds weight to the importance of the quality of children's everyday experiences and interactions in promoting optimum development. The concept of agency is discussed further below.

[28] Neagu, M. (2017). Young Adults' Perspectives on Their Experiences of Different Types of Placement in Romania (Doctoral dissertation). Personal communication from the author but available for public access at ORA (Bodleian library public access)

Summary

- The complexity of both the needs of many children with disabilities and the deinstitutionalization process requires a lifecycle model and a systemic approach to be taken to the change programme to address the common problem of issues being addressed separately rather than exploring the relationships between the factors and the way in which factors impact on each other, positively or negatively
- The use of Bronfenbrenner's eco-systemic model provides the link between individual development and the systems in the child's environment emphasising that development is a highly interactive process and the early years remain an extremely critical window for maximising development
- The quality of children's everyday experiences is key to maximising development and functioning, particularly the experience of close relationships and developing attachments which are the fuel of development
- In order to promote optimal development for children with disabilities, assessment processes must focus on functioning within a normative framework rather than a fixed categorisation system which reduces access to services and drives institutionalization
- The Framework for the Assessment of Children in Need and their Families provides a child-development based model for assessing children and their families and offers a common language which supports multi-disciplinary working, while the Dignities and Capabilities Framework has a highly relevant focus on children's sense of control and agency in their own lives which is too often disregarded in relation to children with disabilities

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PART FOUR:
CORE ELEMENTS OF A CHILD-CENTRED PREVENTION AND DEINSTITUTIONALIZATION PROCESS FOR CHILDREN WITH DISABILITIES

Developing the context

66. While political will is key to the realisation of deinstitutionalization programmes, all the cross-sectoral effort must be underpinned by a passion fuelled by a sense of social justice towards people with disabilities. Passion is the cornerstone of the deinstitutionalization agenda- the Government, media, families, professionals and public must feel strongly about the injustice for adults and children with disabilities in institutional care and support the changes, including those changes which may impact on their own lives such as their child attending school with children with disabilities. Too often passion is felt by the parents of children with disabilities, front line workers and NGOs but not often enough by either those responsible for delivering deinstitutionalization or by the communities in which people with disabilities have a right to live.

67. Prevention of entry is particularly key to closing institutions as it is impossible to close them if there is continuing demand. Too often in the region, demand continues because they are believed to be part of the system to provide "needed" specialist support to children with disabilities, in segregated environments and hidden from the rest of society. A vicious circle exists in which segregation and lack of visibility limit demand for change, lack of demand for change inhibits the development of new professions and local community- based services and lack of effective professionals and local services drives institutionalization.

68. In all the countries visited to inform this work, there were activities and services being developed which are highly relevant to supporting a deinstitutionalization agenda for children with disabilities. However, they were not being conceptualised as part of that process, so while the intentions and services are good, the impact on deinstitutionalization is limited and/or unmeasured. Creating Early Intervention Centres (EICs) was a major priority for all countries visited but they are not yet available at scale and are not being directly linked to prevention and deinstitutionalization targets, particularly for closing baby houses. While generally run by health services, their potential for providing a resource for kindergartens and primary schools to increase and sustain their capacity to provide inclusive or at least integrated education was not being exploited, even though the importance of health and education services working together in early years for children with disabilities is well documented. Many innovations in early years and primary school inclusive education were visible, but again, with honourable exceptions, it was seen as a local service for the local community and not linked to return home from far flung institutions.

69. Another key factor is that much innovation is provided by NGOs as short-term pilot or innovation projects[29]. However, such services too often develop in isolation and when the pump-priming funding ends there are no arrangements for the service to be mainstreamed (if successful) at local or national level and it folds, leaving vulnerable children and their parents without the resource on which they have come to depend. Sustainability is addressed in the discussion about finance in Part Seven of the guidance.

Key elements of the system

70. **Attitude change:** the work on deinstitutionalization must be underpinned by a strong sense of social justice and belief in the capacity of many, if not most, people with disabilities, including children, to lead productive and fulfilling lives, once the barriers are reduced.

71. Attitude change is needed at every level and in every part of the system. It involves ensuring that professional training across social work, health and education services addresses the issues, that the public see children and adults with disabilities in positive roles, enjoying and achieving, employed in their communities, being on stage and on television, in sports arenas as actors in their own lives. Education plays a particularly key role here as inclusive education ensures that all children grow up understanding and respecting difference and, with their supportive parents, drive the attitudinal change.

[29] UNICEF (2017). Situation Analysis of Children with Disabilities in Bosnia and Herzegovina. UNICEF

72. Many parents talked about the long-term negative impact of the attitudes of neo-natal staff when informing them about their child's disability and future prospects. Yet the Paralympics and other visible sporting events have provided opportunities for young athletes with disabilities to succeed in sport and be seen across the world. In the ECA Region, who can be champions for these children beyond their parents? Where are the prominent people in politics, sport or the media who have a child or relative with a disability? How can they be harnessed as champions? In addition, where are the people with passion who don't have a personal connection with disability – it is not the responsibility of people with disabilities and their carers to generate the changes although they are a key resource for demanding and supporting change. Many of these elements can be included in media campaigns and public opinion surveys to generate not just passive support but a rights-based demand for deinstitutionalization and community- based living.

73. **Recognition:** one of the biggest barriers to attitude change is the inability to recognise people with disabilities as people and the impact of this lack of recognition is well- described by Fraser:[30]

'To view recognition as a matter of status means examining institutionalized patterns of cultural value for their effects on the relative standing of social actors... To be misrecognised, accordingly, is not simply to be thought ill of, looked down upon or devalued ...It is rather to be denied the status of a full partner in social interaction, as a consequence of institutionalized patterns of cultural value that constitute one as comparatively unworthy of respect or esteem.'

74. **Creative partnerships:** any successful deinstitutionalization process must be built on effective and energetic cross-cutting partnerships, both vertically and laterally, to ensure that political and professional rivalries and local and Ministerial turf wars do not undermine or halt progress. Rather than threatening a loss of resources or power, partnership working makes everyone collectively more intelligent about the issues and potentially increases resources available to support change. This is particularly important for resource allocation since one government department or local service such as the 'owners' of the institution may need to give up resources to enable more appropriate provision such as early intervention services or foster care services to be developed.

75. An interesting piece of work undertaken by David Le Blanc in relation to the sustainable development goals (SDGs)[31] demonstrated an important mapping process for linking the different goals through their targets in a way which visually shows the connections and congruence between the goals and priorities of the different agencies. This process could be used in developing a deinstitutionalization strategy for children with disabilities to identify key stakeholders and their current priorities and goals - Ministries, services such as health and education, DPOs, local government, parents, carers and children - and the partnerships which need to be made with others in order to deliver them. It also has the advantage of developing these key partnerships at an early stage and identifying the synergies or otherwise between the relevant goals and priorities which need to be addressed. **Appendix 1** shows an example from Le Blanc's work.

76. In discussions about Le Blanc's nexus model however, it was concluded that *'Although such models have the potential to significantly increase partnership impact, they are much more complex and require more management skill and resources than conventional sectoral (silo) partnerships. Furthermore, taking into consideration cross-sectoral linkages across various goals and targets, financing of these partnerships will be challenging as investments made to achieve a given goal influence the approach, resourcing and*

[30] Fraser, N. (2000) Rethinking recognition. New Left Review, 3, p107. Quoted in McNeilly, P., Macdonald, G., & Kelly, B. (2015). The Participation of Disabled Children and Young People: A Social Justice Perspective. Child Care in Practice, 21(3), 266-286. https://doi.org/10.1080/13575279.2015.1014468

[31] Le Blanc, D. (2015) Towards integration at last? The sustainable development goals as a network of targets. DESA Working Paper No. 141 ST/ESA/2015/DWP/141

effectiveness of the delivery of others. It would require strong coordination between key funders, including co-financing of partnership initiatives, joint fiduciary frameworks and joint progress reporting.'[32] Developing and maintaining the partnerships must be a permanent activity within the delivery plan and is an area where UNICEF COs could play a key role.

77. Identifying these interdependencies will secure commitment from the partners, support the process of identifying priorities and sequences of action and maximise available resources across sectors. It will also show the mutual benefits for other partners in engaging in the deinstitutionalization process and highlight where there is a need for resource transfer. Importantly it puts the closure of institutions in a broader policy context and reduces the likelihood that the institutions themselves will be left to manage the process and find their own legacy.

78. However, institutions impact not only on residents but on staff who work there for long periods- their own thinking becomes institutionalized. In Macedonia, two small group living units for adults had been created within an old, large institution for children and adults, with donor support. The residents had very much enjoyed being taken to a beauty salon in the local area, and, recognising this, staff had arranged for a local donor to fund a beauty parlour in the institution.

79. There is a creative aspect to this work in thinking widely about who the delivery partners might be. For example, a project in England worked with the arts community to develop programmes for children in care to enhance their creative skills.[33] In the Region what role could artists play in developing communication methods to support children leaving institutions? What role could they play in supporting children in new small group or family type homes, stimulating play activities and curiosity? What role could the private/business sector/donors play on Steering Groups and funding some of the developments? Being part of the wider project might help them understand the need to switch funding away from buildings and over-specialised equipment to funding new professions and evidence-based ways of working.

80. What is important is that each of the partners understands their unique role and contribution to the goal and to have tasks to complete in relation to it for which they are accountable. Too often attendance at Steering Groups diminishes after initial enthusiasm as it loses priority and people cease to be sure what they are doing there, especially if they were not part of the original developments. Ensuring that NGOs, including DPOs, are around the table both helps with mainstreaming project activity, if it has been effective, and also brings the voice of users to the table, though that is not a substitute for direct consultation and communication with people with disabilities. NGOs and DPOs have considerable experience as advocates and can also help with the engagement processes.

81. **Participation:** the participation of all stakeholders is another essential underpinning for delivering deinstitutionalization and developing community-based services. It is about participation at national and community level - see earlier section on communication and public awareness - as well as the key stakeholders such as children, parents and wider families. Without genuine participation, the change process will stall.

82. There is however little evidence of the children with disabilities being engaged in a meaningful way in the setting up and design of alternative provision or being given any choices about where they want to live. In one institution visited, the change process was being managed by experts who were providing 'intensive therapy' but did not expect that children could be engaged in a meaningful way in terms of having real choices and understanding change.

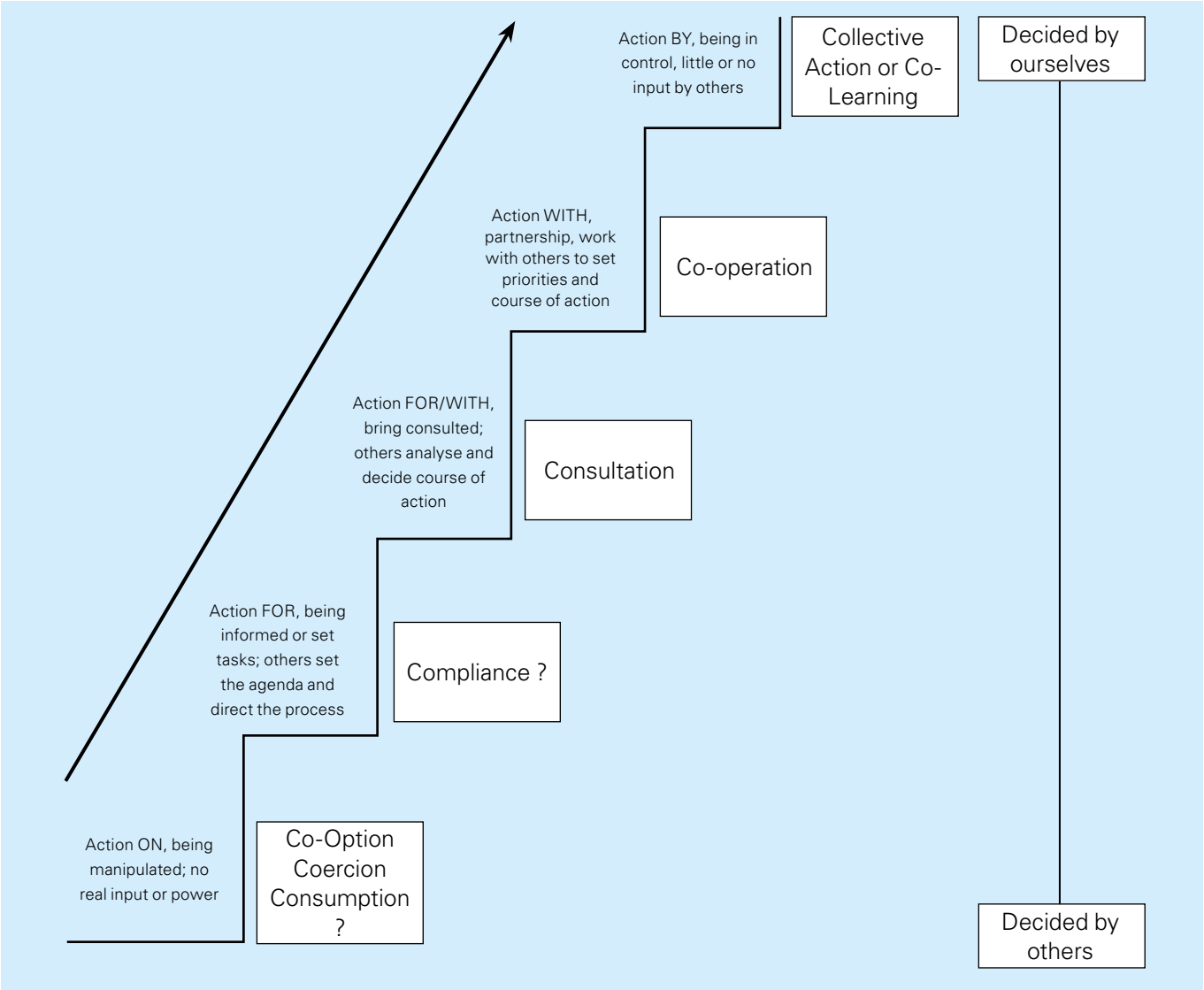
83. The ladder of participation below shows the different stages of what is called participation and demonstrates the serious limitations of much of this activity for children with disabilities.[34]

[32] ECOSOC Partnership Forum. (2016). Breaking the Silos: Cross-sectoral partnerships for advancing the Sustainable Development Goals (SDGs). ECOSOC

[33] Chambers, H. (2008) People with passion getting the right people around the table Principal Officer National Children's Bureau (NCB)

[34] Arnstein, Sherry R. "A Ladder of Citizen Participation," Journal of the American Planning Association, Vol. 35, No. 4, July 1969, pp. 216-224.

Figure 6: The ladder of participation



84. Children with disabilities struggle to move beyond the third step of the ladder as the process remains entirely adult -led. The barriers to their meaningful participation reflect the wider barriers to deinstitutionalization already discussed- poverty of expectation (they wouldn't understand anyway), lack of access to communication tools for sensory impaired children (only talking counts), lack of imagination in creating play and other resources that would support participation by children with intellectual difficulties. Where children are enabled to have a voice, it is clear that they are important actors in their own lives. Imaginative consultation with children with disabilities in Albania for example, revealed their hopes and fears for their adult futures which opened up new key areas for development, particularly in taking a longer-term life cycle view of children's lives:

'Consulting with children, and not only adults, has emphasized the importance of life- course planning for children with disabilities from birth and early childhood through to young adulthood and independent living. If parents have greater confidence in the future for their children from the outset, they will be better able to support their ambitions and hopes for one that is positive.'[35]

[35] UNICEF (2018). We all Matter Situation Analysis of Children with Disabilities in Albania. Op.cit

85. Another example is provided by the Council for Disabled Children (CDC) in the UK.[36] Making Participation Work includes a young people's advisory group, FLARE, which is formed of twelve 13-25 year-olds with SEND (special educational needs and disability) from around the country, to advise, challenge and support the government about how the SEND reforms would affect disabled children and young people directly. When governments give a voice to children with disabilities, it provides an important message to the public and other sectors about their value and visibility.

86. **Workforce, assessment and intervention processes:** the categorisation system described above is a major driver for institutionalization because of the way it depresses expectations and limits the access of children with disabilities to services. Many countries in the Region have already planned or are planning shifts to functionality assessments as described earlier but the conduct of functionality assessments requires new knowledge and expertise across professions and new training. UNICEF have provided a booklet to support the understanding and use of the WHO Family of International Classifications (WHO-FIC) and the ICF and ICF-CY in particular. [37] [38]

87. In Macedonia a major training programme is underway to introduce the WHO International Classification of Functioning (ICF) across a number of services, requiring significant intersectoral work. Training for GPs has already been provided and screening tools are being introduced for ASD. However, there are significant resource implications in moving from a fixed categorisation by disability such as Down's Syndrome to a full assessment of the individual child's functioning and the provision of services to improve functioning which must be factored in to the deinstitutionalization plan.

88. In countries visited as part of the assignment, the absence of a locally functioning and trained social work service limited the assessment of families' needs and circumstances. Developing the context and implementation plans therefore need to include workforce mapping to ensure that children are not deinstitutionalized but left with fewer services. Workforce issues were also exacerbated by old-fashioned methodologies which were not all benign. Interventions for hearing impaired children, and the underpinning attitudes, are particularly poor and provide an important illustration of these issues.

Hearing impaired children

Prevailing professional beliefs and attitudes:

- Hearing impaired children should always be aiming to learn to speak, to whatever degree they are able
- The role of special boarding and other schools is to teach speech
- If a child cannot learn to speak s/he is unintelligent and not able to be educated and needs a different institution
- Sign language is not an acceptable form of communication

Impact of the attitudes

- in Kyrgyzstan classrooms still had metal instruments which could be used in young children's mouths to 'help' them to shape words which the children were frightened of
- No settings in the 3 countries were using any form of sign language because the gold standard is speech
- A hierarchy is created between children who have some capacity for speech and those who do not
- Those who cannot speak clearly are left without any means of communication

[36] https://councilfordisabledchildren.org.uk/our-work/participation/practice/making-participation-work 8.1.19

[37] WHO. (2001) International Classification of Functioning, Disability and Health (ICF). WHO

[38] UNICEF. (2014) Definition and Classification of Disability - Companion Technical Booklet. UNICEF

89. Learning disabled children were equally disadvantaged by speech difficulties. Again, the standard is speech and those without were left to communicate as best they could. Little or no speech was regarded as part of the intellectual disability and therefore there was no activity to support speech development. No setting visited during country visits was using Makaton[39], a highly accessible simple sign language for children with intellectual difficulties which can both act as a bridge to spoken language where speech development is delayed or as an effective communication alternative, enabling children to communicate their needs, wishes and feelings. A child in Macedonia who had recently moved from a large institution to a small group home was seen sucking from a tap to show she was thirsty. Her ability to communicate would be significantly improved by Makaton signing.

90. In spite of the work that has been done across the Region, the terminology for the most common profession working within the countries visited is 'defectologist' which in itself is part of the problem. The content of training is unclear but discussions about it suggest that it does not reflect the most up to date evidence, understanding and methodologies for supporting children with disabilities and their families. While efforts are being made to phase out the use of the term because of its derogatory nature, it is the underpinning skills which must be addressed. These difficulties are compounded by the lack of other professionals such as speech therapists, occupational therapists and physiotherapists.

Summary

- Prevention of entry is particularly key to closing institutions as it is impossible to close them if there is continuing demand. Too often in the region, demand continues because they are believed to be part of the system to provide "needed" specialist support to children with disabilities, in segregated environments. This specialist support is seen as more important than parental relationships and support.

- There are activities and services being developed which are highly relevant to supporting a deinstitutionalization agenda for children with disabilities. However, they were not being conceptualised as part of that process, so while the intentions and services are good, the impact on deinstitutionalization is limited and/or unmeasured. Promoting a multi-disciplinary and multisectoral approach to deinstitutionalization is therefore key

- Key elements of the system to be addressed include attitude change- both in the recognition of those with disabilities as people with rights and to the negative stereotypes held by many professionals in the Region; creative and effective partnerships across government ministries, services and professionals to generate a shared commitment to goals and objectives; participation of children and adults with disabilities and their parents and carers; improvements to professional practice

[39] The Makaton Vocabulary Development Project. (1999). Makaton - core vocabulary – signs Spiral-bound.
The Makaton Vocabulary Development Project.

PART FIVE:
THE PURPOSE OF PROVISION FOR CHILDREN WITH DISABILITIES AND MEASURES OF QUALITY OF CARE

'Young children experience their world as an environment of relationships, and these relationships affect virtually all aspects of their development.'[40]

[40] National Scientific Council on the Developing Child (2004) op.cit. Accessed 6.1.19

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Clarifying the purpose of provision and using the developmental framework for assessing the suitability of provision for children with disabilities and their families

91. While there are different views about the suitability of particular types of provision for children with disabilities, what matters is whether any provision can offer the most appropriate way to respond to an individual child's assessed needs. Such an approach can accommodate much of the debate surrounding the appropriateness of different care settings for children with disabilities.

92. Information from a needs analysis (discussed in detail in Part 6) will inform the requirements for the range of provision, including support to birth families and family and friends carers, foster carers and adopters. For an individual child, however, it is important that there is clarity of purpose of the particular care setting in meeting the goals of their care plan.

Statements of purpose for provision

93. **Foster care:** it is essential to use the information from the needs analysis to map the requirements for different types of foster care- emergency, short-term, respite, long- term, babies and young children - as too often in the region foster care equates to long- term care as there are not the social work and other services to support return home. It should be reconceptualised as a family support service as well as a long- term resource for children who cannot live with birth or wider family.

94. The approval process for foster carers will then reflect the type of foster care being offered and the number of children they can care for. This is not to say that there should not be flexibility in terms of a short term foster carer keeping the child if their care plan changes from short term to longer term care, but it requires a specific re-assessment to ensure that the foster home remains the most appropriate place to meet the child's needs.

95. **Small group homes and family type homes:** the draft White Paper on SGHs identifies 4 main functions in relation to children with disabilities:

- As a medium/long term option for adolescents who do not want another family or for the small group of children with disabilities whose needs and capacities are such that it would be difficult for an individual family to provide full time care. These children will be there as a result of a careful assessment of individual need and supported by an individualised plan for the child's care through to adulthood where necessary
- As a transitionary provision for children with or without disabilities who are so institutionalized that they cannot move directly from the large institution to family- based care. These children will have very specific needs which will be met by the implementation of a care plan setting out the support required to enable a move to family-based care
- As a transitory provision for children with or without disabilities where the family and community - based services have yet to be developed. In these circumstances no SGH should be developed unless as part of a wider, long-term, stepped strategy to develop the necessary family and community- based care.
- As a shared care resource for parents of children with severe disabilities and/or children in need of palliative care

96. Clarity of purpose for the home then determines which children go into the home, how long they will stay and what should be happening while they are there. The following examples from country visits, however, illustrate some of the complexity of defining and categorising such provision.

97. In one SGH visited in Kyrgyzstan for severely disabled children, although it was physically small and homely and loving, there were a lot of additional professional staff on site involved in the care of the children who had little contact with birth families and therefore little opportunity to develop attachments. The home was making great efforts to contact parents and encourage their visits with a view to a return home in the future but while clearly considerably better than the large institution was functioning nevertheless more as a small institution than a home.

98. There are many concerns about the role of SGHs and family-type homes. Within a desired continuum of services for children with disabilities, the construction and running of SGHs may take a large share of the budget and thus jeopardize the development of more community-based care and prevention services. A particular risk of SGHs for children with disabilities is that professionals are concentrated around the home, supporting a relatively small number of children when they could be a resource for the wider community, enabling more children to benefit and supporting the prevention agenda.

99. At the same time there is also recognition that small-scale specialist residential care, can play an important (albeit smaller) role in the child protection and child care system. In the context of dismantling large- scale institutions, there may be a slightly larger role for SGHs in the short to medium term, given the profiles of children who have spent years in harmful large institutional care and may be less inclined or indeed able, to move quickly into family-based care. In Belarus, the most positive and loving relationship between a child and a carer was seen in a small family type home of 11 children. An important feature of the home was that it did not have additional staff and was run by a couple providing strong parental roles, thus functioning as a large family rather than a small institution.

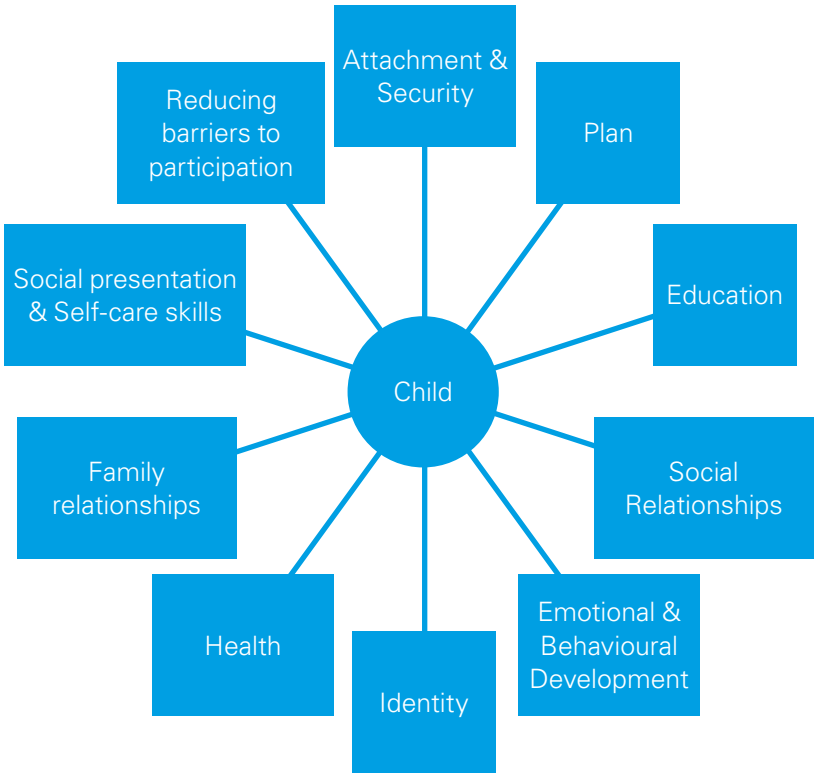
100. The family-type homes in Belarus, for respectively 9 and 11 children both with and without disabilities, were run by married couples with no additional staff. As cited above the children with disabilities were clearly happy and enjoying a good and loving relationship with their carers but it was equally clear that older children in the home were providing a lot of practical help. They may have been very happy to do that but in that context it will be important to ensure that they have an opportunity to express their views about it. Is that what older children in a large family setting generally do? Is it the same in non-biological family units? What is an appropriate number of children for a family-type home?

A developmental model for assessing suitability and measuring quality

101. A developmental approach is helpful in addressing the quality of provision to meet children's needs, in terms of the family home or alternative care setting, the approach to the assessment of a child's needs and the supports and services necessary to optimise the child's development as it focuses not on the type of building but what goes on inside it- what is the quality of the child's daily experiences? One very powerful tool for responding to this question is to observe a particular child during a visit to a child's home or alternative care setting and to write an account of a day in the life of that child written in the first person. It is not the weekly visit from a therapist or other specialist which will impact on a child's development but the quality of the multiple daily interactions with other children and adults in the setting although the therapists play an important role as a specialist service and possibly also as a resource for front line practitioners.

102. Using the Assessment Framework set out in **Figure 2**, **Figure 5** below provides an approach to assessing the suitability of provision. A more detailed version of this diagram is provided at **Appendix 3** and a worked example from an assessment of an institution is at **Appendix 4**.

Figure 5: A child-centred approach to assessing suitability of provision for children with disabilities



Core concepts of the diagram

103. **Health:** *Includes* growth and development as well as physical and mental wellbeing. The impact of genetic factors and of any impairment should be considered. Involves receiving appropriate healthcare when ill, an adequate and nutritious diet, exercise, immunisations where appropriate and developmental checks, dental and optical care and, for older children, appropriate advice and information on issues that have an impact on health, including sex education and substance misuse

104. **Education:** Covers all areas of a child's cognitive development which begins from birth. *Includes* opportunities: for play and interaction with other children; to have access to books; to acquire a range of skills and interests; to experience success and achievement. Involves an adult interested in educational activities, progress and achievements, who takes account of the child 's starting point and any special educational needs

105. **Emotional and Behavioural Development:** Concerns the appropriateness of response demonstrated in feelings and actions by a child, initially to parents and caregivers and, as the child grows older, to others beyond the family. *Includes* nature and quality of early attachments, characteristics of temperament, adaptation to change, response to stress and degree of appropriate self- control

106. **Identity:** Concerns the child's growing sense of self as a separate and valued person. *Includes* the child's view of self and abilities, self- image and self -esteem, and having a positive sense of individuality. Race, religion, age, gender, sexuality and disability may all contribute to this. Feelings of belonging and acceptance by family, peer group and wider society, including other cultural groups

107. **Family and Social Relationships:** Development of empathy and the capacity to place self in someone else's shoes. *Includes* a stable and affectionate relationship with parents or caregivers, good relationships with siblings, increasing importance of age appropriate friendships with peers and other significant persons in the child's life and response of family to these relationships

108. **Social Presentation:** Concerns child's growing understanding of the way in which appearance, behaviour, and any impairment are perceived by the outside world and the impression being created. *Includes* appropriateness of dress for age, gender, culture and religion; cleanliness and personal hygiene; and availability of advice from parents or caregivers about presentation in different settings

109. **Self-care skills:** Concerns the acquisition by a child of practical, emotional and communication competencies required for increasing independence. Includes early practical skills of dressing and feeding, opportunities to gain confidence and practical skills to undertake activities away from the family and independent living skills as older children. *Includes* encouragement to acquire social problem-solving approaches. Special attention should be given to the impact of a child's impairment and other vulnerabilities, and on social circumstances affecting these in the development of self-care skills

110. **Reducing barriers to participation:** Concerns the child's access to speech and language and other relevant therapies; electronic aids and equipment to maximise participation; the reduction of other barriers in the child's environment

111. **Plans:** Concerns the need for each child to have an individualised assessment of their developmental needs and a plan for meeting and monitoring those needs in the context of the plan for their current and future care

Key criteria for suitability

112. The most important criteria for considering suitability of alternative care as well as the quality of care being provided at home is its capacity to support children's secure attachment to a consistent adult. In most cases this will be a child's parent or close relative but may be a foster parent or with a worker in a small group setting. It is not possible to provide this individualised relationship in a large group setting with rotating staff. Nor is it possible for children to maintain healthy attachments to parents/other adults they see rarely and/or intermittently while living full time in an institution or boarding school some distance from home. Secure attachments are formed through a relationship which is present, consistent, predictable and responsive.

113. The child's age is also an important factor in determining suitability. The situation analysis in Albania on children with disabilities[41] found that some adolescents liked their weekly boarding school where they had friendship groups and felt freed from overprotective parents. Their capacity to understand and measure time and to tolerate separation is significantly different from that of a much younger child who needs a continual, responsive and predictable physical presence to sustain their attachments.

Using a dignity and capabilities framework

114. Another way of conceptualising the assessment of quality of care is provided in the study of Romanian care leavers referred to above[42]. The study combined models which look at dignity from the perspective of the care experience and the capabilities approach from the adult outcomes perspective to provide a framework of quality of care measures. The framework uses Thomas Hammerberg's 3 Ps operationalisation of the CRC[43] which proposes:

- Provision and basic freedoms
- Protection from harm and emotional well-being
- Participation and control over one's environment

115. The model then includes Nussbaum's emerging theory[44], mainly for adults and lists ten capabilities including provisions related to:

- Basic freedoms
- Physical and emotional wellbeing
- Control over one's environment (opportunity, choice, agency)

[41] UNICEF (2018). We all Matter Situation Analysis of Children with Disabilities in Albania. UNICEF

[42] Neagu, M. (2017) op.cit

[43] Hammarberg, T. (1990). The UN Convention on the Rights of the Child and how to make it work. Humans Rights Quarterly, 12(1) quoted in Neagu, M. (2017) op.cit

[44] Nussbaum, M. (2011). Creating Capabilities, The Human Development Approach. Cambridge, MA: First Harvard University Press. quoted in Neagu, M. (2017) op.cit

116. The detailed framework is shown in **Appendix 5** and has particular relevance for children with disabilities as it incorporates the participation issues and basic freedoms and control over the environment which are all too often missing from their experiences.

Assessing quality of care in the home or wider family setting

117. In focusing on deinstitutionalization, it is important to assess the quality of children's experiences in the home setting. Either of the models identified above can be used but the Assessment Framework, which was developed for children in community-based settings provides a strengths-based framework which can be used to identify parental support needs as well as identify children at risk of harm or developmental impairment. In countries in the region where social work is underdeveloped and resourced it could be a helpful tool.

Summary

- Identifying the purpose and the required standards and quality of care across the range of provision for children in a way which creates a clear and level playing field is key to ensuring the right match between the child's needs and the appropriate setting. Standards will also ensure that there is an equitable approach to identifying acceptable and unacceptable quality of care

- Statements of purpose identify which children, with what level of need and overall care plan, the home (foster or residential) is suited to care for. This ensures that the home is suitably staffed and/or trained for the children and ensures that children do not drift in alternative care

- Statements of Purpose also ensure that small group homes are only developed for particular purposes in relation to assessed need and are not used to warehouse children in smaller institutions for long periods of time

- In determining suitability and appropriateness of care, a developmental approach is helpful as it places the child and the child's daily experience at the heart of the assessment. The models proposed use frameworks which are adaptable to take a lifecycle approach, encompassing different ages and stages with a focus on increasing children's attachments, functioning and agency

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PART SIX:
PLANNING FOR CHANGE

Identifying the children and priorities

118. Countries which are signatories to the CRPD are obliged by Article 31 to collect *'appropriate information, including statistical and research data to enable them to formulate and implement policies'* which will enable them to implement the Convention.

119. In order for governments and other agencies and stakeholders to develop a targeted, sustainable, prevention and deinstitutionalization agenda, they must have information about who the children are, the nature and range of the disabilities, which children are still at home and in what circumstances, the profile of those children currently in institutions, including boarding schools and small group homes, and best estimates of who might constitute the hidden group of children with disabilities and why. It is not only a matter of **who** the children are but **where** they are so that scarce resources can be targeted where they are most needed.

120. It is well recognised and documented that collecting such information across the region is extremely difficult due to lack of common definitions between countries and across government departments and services. This does not mean that data should not or cannot be collected- start with what is available and use it to demonstrate the value of good data and to drive improvements.

121. The number of children in residential/institutional care is known as are the number of children in foster care. The information on the stocks and flows/entries and exits into the alternative care system is less widely available. More information is needed on the reasons for admission, the situation of the child and family status, whereabouts of siblings and whether relatives have been contacted with regard to providing care. This information will be useful for planning re-integration but will also help in planning services to prevent separation.

Understanding and identifying needs, costs and outcomes

122. Data is particularly important for deciding on priorities in a context of scarce resources and questions as to where investment could have the greatest impact will be specific to each country context. Understanding the nature of the difficulties and levels of functioning of the children in institutions will help determine priorities for support services in the community for parents and families and for identifying the balance of provision between small group homes and family foster care as well the necessary transition periods for the children.

123. Being able to cost children's placements accurately facilitates comparisons between the relative value of different types of care and makes it easier to estimate the potential benefits of introducing a range of different services for enabling children to stay with birth and/or extended families and for new settings such as foster care. Is there a long- term benefit to the child and the country's finances in providing early help? How do we calculate this? As the authors[45] point out in a European study on outcomes and costs of deinstitutionalization:

The (complex) links between costs, needs and outcomes sit at the heart of the evidence base on which to build a strong economic case for making the transition from institutions to services in the community. In a good care system, the costs of supporting people with substantial disabilities are usually high, wherever those people live. Policy makers must not expect costs to be low in community settings, even if the institutional services they are intended to replace appear to be inexpensive. Low-cost institutional services are almost always delivering low-quality care.

124. Work has been done in the UK to develop a simple 'bottom up' costing model called a Cost Calculator for Children's Services which identifies different types of placements, costs for individual children and costs for groups of children according to needs, gender, age, placement type or provider using local data and enabling 'what if scenarios'[46]. This is particularly important when seeking government

[45] Mansell et al. op.cit

[46] Holmes, L. and McDermid, S. (2012) Understanding costs and outcomes in child welfare services, London: Jessica Kingsley Publishers.

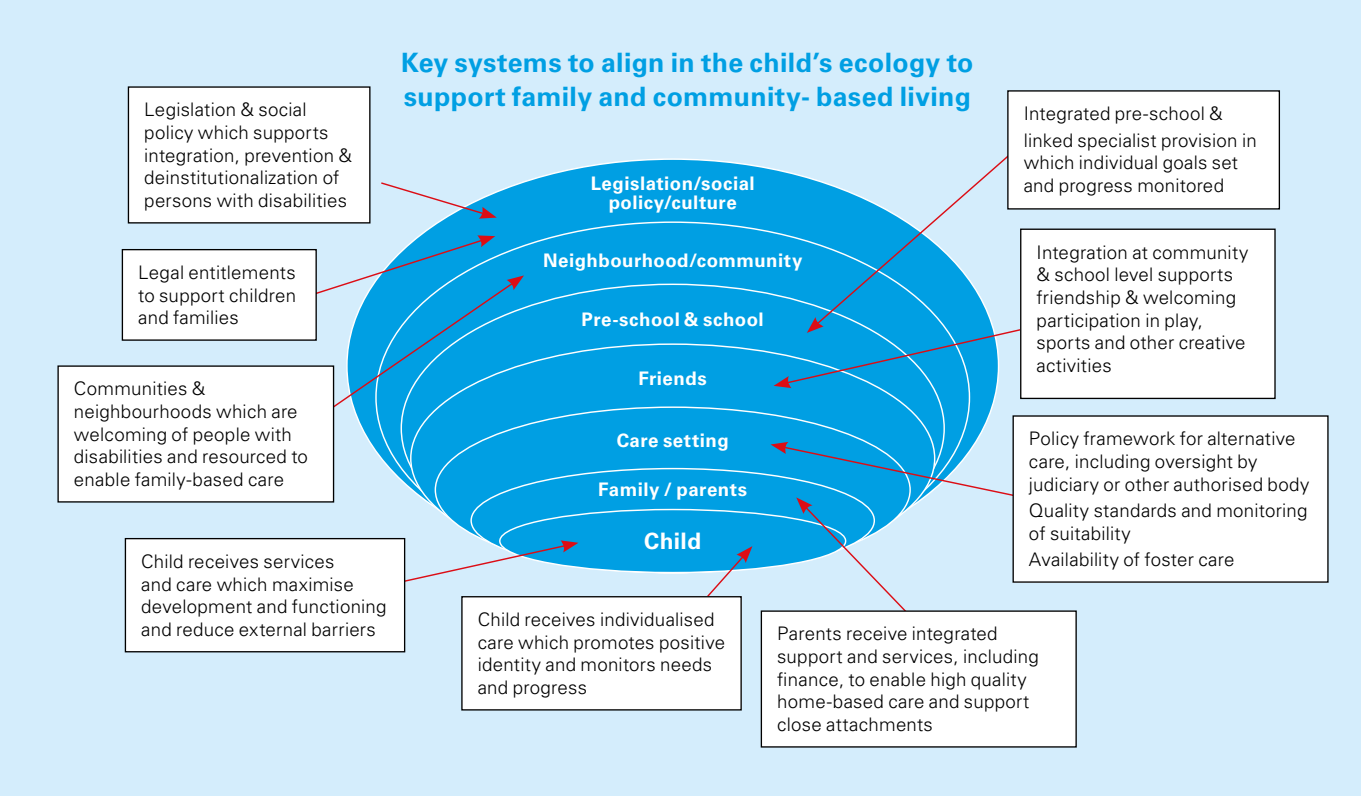
and financial support for major reforms. The tool and underpinning conceptual framework have been found to have applicability beyond the English child welfare system.

125. In addition, work has also been done on an approach to economic modelling that can be used in a number of ways to inform decision-making, advocacy, research and practice development. The Childonomics approach[47] *'is based on cost-consequence analysis (CCA) and incorporates elements of social return on investment methods including service user perspectives in the analysis of return on investment. CCA presents costs and outcomes side by side in a disaggregated manner; it is a form of cost-effectiveness analysis which presents the range of benefits identified alongside costs incurred without aggregating them in a single metric (e.g. a cost-effectiveness ratio), leaving the users of the methodology to incorporate their own considerations when judging the merits of an intervention or programme'*.

Designing the system

126. Having identified the context for reforms in a particular country, the next phase is to assess the elements of the system which need to be developed in order to deliver them. The diagram below uses Bronfenbrenner's model to show the core elements of the system which need to be in place to support deinstitutionalization and provide effective community-based support for children and families.

Figure 3: Key systems to align in the child's ecology



[47] Rogers, J. Kennedy, J. Gheorghe, A.and with contributions from Kuzminskyi, V and Costea, C. (2017) Childonomics : Malta and Romania: lessons learned from applying the Childonomics conceptual framework and methodology in practice. P4EC and IFCO

A framework for community-based services

127. In considering the range of services which will be required to support children with disabilities in the community and in taking a 'think child not disability' approach, it is helpful to use the framework of universal, targeted and specialist services. The key point is that all services need to be available and accessible to children with disabilities, from the local school and health services to the local playground or the local bus. The framework below takes a hearing- impaired child as an example:

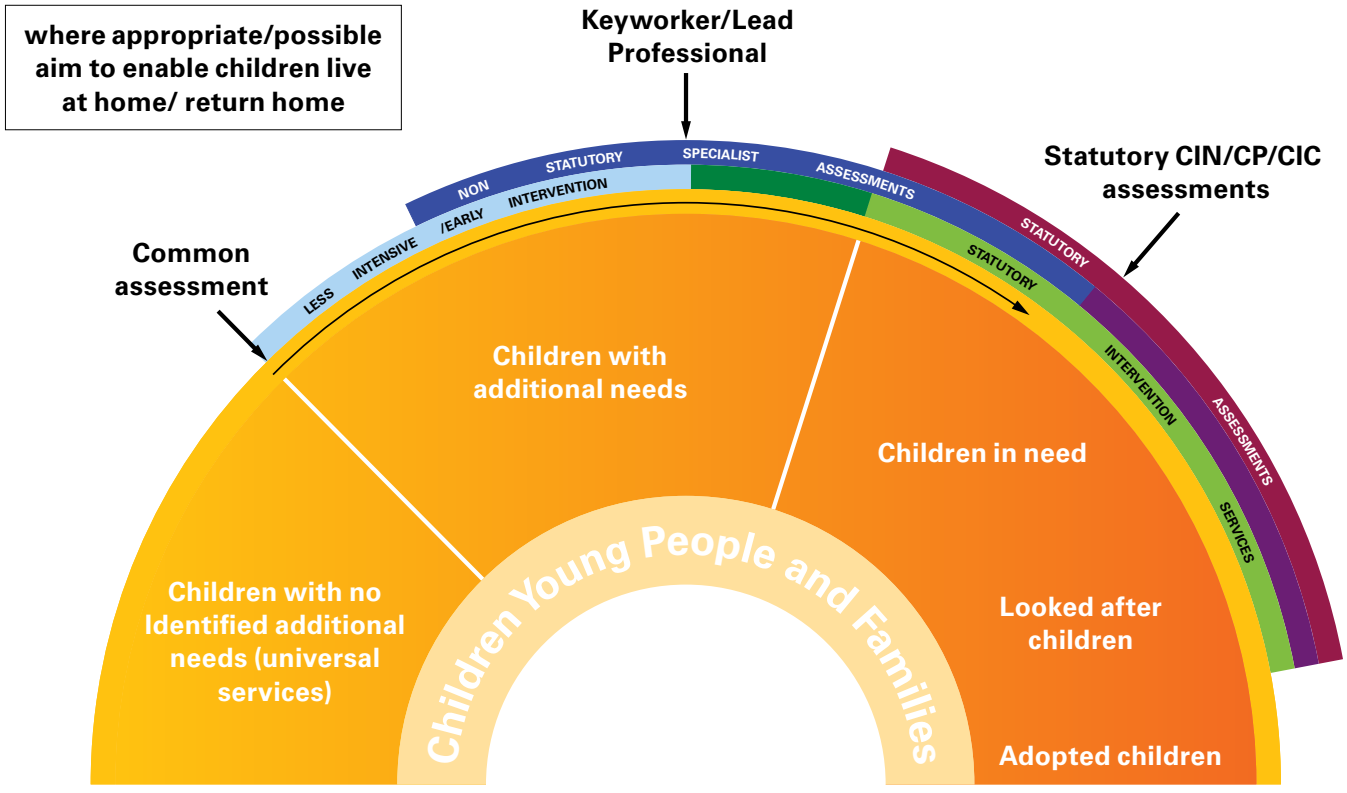
128. **Universal services** support the whole population, i.e. whole class or whole setting/ school or all children in the local area and ensure that all children have appropriate language and communication opportunities, housing and individualised support. This level includes workforce development, access to appropriate information and creating communication friendly environments.

129. **Targeted services** offer specific support for those children and young people who are felt to be vulnerable in relation to speech, language and communication. The group is wide ranging and includes children with delayed language and communication skills who, following targeted intervention, will return to the universal tier, through to identification of children who may go on to have longer term needs. This level includes small group and individual targeted intervention approaches such as language groups, narrative groups, social communication skills programmes and phonology programmes.

130. **Specialist services** are offered in addition to the universal and targeted for those children and young people who require highly individualised and personalised interventions. This group includes children with complex learning and communication needs and those children who are cognitively able and have specific speech, language or communication needs.

131. The model below shows the way in which services and interventions can be mapped against groups of children, level of need and type of service for strategic planning purposes. This helps to identify gaps in services at particular levels of need but also supports the development of coherence between services, particularly for children who have long-term and profound needs and who will need to access different levels of service across the lifecycle.

Figure 4: Continuum of needs and interventions model



132. Appendix 2 provides a model taken from a Canadian project called Promoting Family Wellness which uses the three-tier model described above alongside Bronfenbrenner's ecological systems model to illustrate a range of integrated services that might need to be available by level of need and system level.[48] This could be developed for national or local contexts by countries in the region.

133. Having identified needs and understood the range of services which should be in place the components of the family and community based services which need to be in place are set out below.

Core components of family and community-based services

Professionals and practitioners

134. Any initiative designed to prevent the institutionalization of children with disabilities requires the development of professionals willing and able to adapt their practice to new effective ways of working and provided with opportunities to do so. The failure to change practice on the ground is a major reason for the failure of change programmes in the social care field. Fear of change, of job losses, of being required to move out of a comfort zone, lack of re-training opportunities, all jeopardise the delivery of change.

135. Real participation by staff in institutions is also key to the success of changes. It is not enough to expect that altruism- understanding that closing the institutions is better for the children and adults in them- will provide sufficient motivation when people feel that jobs and income are at risk, especially in contexts where there are few alternatives. The institutions themselves are sometimes left in charge of determining the future of the site/building which creates an incentive to maintain the institution in some form such as smaller living units for adults. Staff must be offered alternative training to adapt their practice in the same field or to move to a new type of employment as a positive choice.

136. A lack of an appropriately qualified social work profession is a particularly significant barrier to change across the region as it is not possible to provide effective help to families across the early help and child protection spectrum. and boarding schools provide an all too easy way out for under-resourced professionals. It is clear that much practice with children with disabilities does not reflect current pedagogy in the field - for example the non-use of early interventions such as portage services or Makaton to enable intellectually disabled children to communicate. Nor does it reflect the major advances in brain science which are driving new understandings about children's development which is essential if the change to a 'think child not disability' approach is to be achieved.

137. The Hand in Hand parent's organisation for children with Autistic Spectrum Disorder (ASD) in Kyrgyzstan is having to spearhead the development of appropriate services. Through an effective parent-neurologist and paediatrician partnership they have managed to achieve earlier diagnoses and are now seeing children aged 1-3 instead of 8-10 when it is much harder to provide help. But access to specialised therapists with modern methods such as speech and language therapist, physiotherapists and occupational therapists is limited by a lack of training and qualification places in the country.

Communication and public awareness

138. It is clear that public and media attitudes to disability have a huge impact on rates of institutionalization and capacity to de-institutionalize. The effect of decades of keeping children and adults with disabilities out of sight, behind walls and bars in many instances, is that people are not used to seeing people with disabilities in their communities. The media therefore have a major role to play in any de- institutionalization plan.

[48] Nelson, G. Peirson, L. and Prilletensky, I. (eds.) (2001) Promoting Family Wellness and Preventing Child Maltreatment: Fundamentals for Thinking and Action. University of Toronto Press

139. UNICEF in The Republic of North Macedonia recently published a second survey of public attitudes to disability[49] which shows an improvement in public attitudes to disability since the previous survey 4 years ago. However, those who agree (41%) with the statement – "no matter how much the state and the society try and how much money they invest, there is not much that can be done to help the children with disabilities" outnumber those who disagree (37% disagree with the statement). In 2014, this attitude was the other way around (31% agreed, while 42% disagreed with the statement). Undertaking such surveys is essential in addressing the community and cultural barriers to deinstitutionalization.

Parents and carers

140. The importance of children's participation has been addressed earlier. However, the needs and wishes of parents, including foster and adoptive parents, must be at the heart of the reforms, with services responding to need rather than parents and children fitting into existing services. Parents, carers and children must be key actors in the development of the new community-based services. In many countries in the region, however, the engagement of parents in the change process is very limited, particularly if they are deemed 'bad parents' who had their own difficulties and who therefore did not deserve to be involved. In the baby home in Belarus parents were 'allowed' to visit when they wanted but, in reality, had to have a medical check-up and produce a certificate of health for each visit which creates a significant barrier and few parents visited. This was not seen as a cause for concern but rather a confirmation of their unsuitability.

141. Institutions and boarding schools did not see themselves as working in partnership with parents or consulting them. In many institutions across the Region parents were allowed in to watch music and drama performances and some were allowed to help make costumes, but they had no role or input into the running of the setting or the care and education activities.

[49] UNICEF (2018). Follow up survey on Knowledge, Practices, Attitudes towards Children with Disabilities (KAPS Survey)

142. The development of the early intervention and diagnosis centres is providing an opportunity to develop new ways of working with parents and seeing parents as experts in their own child. In Belarus where a number of such centres are being established, the therapists were working in partnership with parents, providing imaginative home-made resources and giving parents skills which they could continue to use with their children in the everyday at home. Parents were described as the most important partners and felt validated in the role as the person who knows the child best. Some kindergartens in Belarus were also trying to develop their role as a wider resource for parents, including particular encouragement for fathers to come to the kindergarten.

143. Culturally and age-appropriate tools and methods will need to be developed to support child and family engagement in the context of disability and enable them to express their wishes and needs in a non-stigmatising way. Increasing levels of participation also increases partnership working between children, families and services. Most countries in the region now have parent-run organisations, often for specific disabilities, which can be an important resource, and suitably trained and prepared parents can act as researchers or interviewers.

Foster care

144. In some countries in the region the development of foster care has supported deinstitutionalization of children with disabilities. In others it remains a marginal service for all children. Foster care is not a homogeneous activity though are core elements to the task. Along with limited foster care services for children with disabilities, it was very difficult to recruit foster carers for young children generally because the costs were seen as higher, not least because a small child requires the full-time presence of an adult who cannot then also work outside the home, but these costs were not reflected in the payments system. This means that babies and young children with disabilities who have the highest need for family care are most likely to be in institutions. The understanding of needs, costs and outcomes over time is demonstrably relevant to decision-making and deinstitutionalization.

Education

145. Access to good local inclusive education is key to prevention and deinstitutionalization and progress in inclusive education must be accelerated to reduce dependence on residential settings to provide education. It is a challenging process as the nature and impact of disabilities is very varied. While there are positive developments in inclusive education at kindergarten level, the process stalls as the children get older and the curriculum becomes more complex. More progress has been made in integration of children with physical disabilities than those with sensory or intellectual disabilities. There is a tendency to view inclusion as a process which will happen organically as young children in inclusive education get older and progress through the school system. However, the evidence does not support this view and it requires a much more proactive approach, particularly at secondary level.

146. In the Republic of North Macedonia in a school which has been working on inclusion for many years, an established inclusion team develops activities to be implemented each year for groups and individual children as part of individualised education planning with parents and class teachers. Short, medium and long-term goals are set. One important outcome of this resource is that it leads to the identification of other children in the school who have difficulties and enables support to be provided to those children, without a formal categorisation. Thus there is evidence of whole-school benefits to inclusion, but it needs much time and dedicated resource to make it work. Many parents had started their child in the local mainstream school but subsequently withdrawn them into specialist provision because they did not think that their child's learning needs were being met appropriately.

Health services

147. There are a number of issues for health services across the region which are key to enable children with disabilities to enjoy family-based care. Attitude change is central to this. The difficulties with the categorisation systems and the necessity of assessing functionality have already been highlighted. In addition, in some countries there are barriers to accessing health services if a child's birth has not been registered or there is a need for the child to spend time in hospital for an assessment/ diagnosis creating trauma for the child and practical difficulties for parents who have to fund their accommodation during the process, take time off work and find care for siblings.

148. Lack of availability of specialists to provide a diagnosis led many parents to seek help abroad in western Europe or the US or were required to travel to neighbouring countries for particular tests. While it is clearly difficult for some low and middle-income countries to fund the range of specialists to cover every type of disability, the use of video-consultations and other technologies could reduce these barriers.

149. Providing therapies such as speech and language, occupational, physio and other therapies maximises the child's functioning as do other aids and adaptations for physical and sensory impairments. As with access to inclusive education, early intervention and diagnosis centres enable parents to be involved and empowered in their child's progress and development from the earliest stage, reinforcing positive relationships with the child and making them less likely to want to place him or her in an institution

Summary

- In order to plan for change, information about the profile of the target population, current provision and future trends is essential in order to identify the scale of the change and target scarce resources appropriately

- Understanding needs, costs and outcomes enables comparisons between different types of provision and an estimation of the potential cost benefits of introducing new types of provision and services

- Bronfenbrenner's model shows how the key systems at different levels in the child's ecology need to align in order to delivered deinstitutionalization, alongside the tiered approach to delivering local services across levels of need

- Core components of effective family and community-based services include positive public attitudes and community acceptance of difference, parents and carers as partners in change, a range of high- quality foster carers, and health and education systems which reduce barriers and promote inclusion

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PART SEVEN:
IMPLEMENTING AND MONITORING THE DEINSTITUTIONALIZATION STRATEGY AND MANAGING TRANSITIONS

'Authors from around the globe… agree that the challenges and complexities of implementation far outweigh the efforts of making practices and programmes themselves'[50]

[50] Fixsen, D., Naoom, S., Blase, K., Friedman, R., Wallace, F. (2005). Implementation Research: A Synthesis of the Literature. Tamps, FL: University of South Florida, Louis de la Parte Florida Mental Health Institute, National Implementation Research Network.

Implementing the strategy

150. Evidence shows that for children with disabilities, the knowledge about what works in deinstitutionalization has not resulted in real change on the ground. A number of reasons have been identified in this guidance:

- There is insufficient passion and will to undertake them
- There is insufficient understanding of the scale of the changes required and their systemic nature
- There is insufficient focus on the detail and planning required
- There is insufficient attention to developing the right partnerships to drive the systemic approach
- There is insufficient understanding of implementation and change processes
- There is insufficient in-country experience of large scale multi-systemic change

151. It is likely that it is a combination of all these factors which accounts for the stalling of progress in the region and countries will wish to identify the weight of each of them for their own situation.

Issues in implementing large scale change

152. The difficulties in delivering change in the public services arena is far from limited to the deinstitutionalization of children with disabilities and much attention has been given to the issues in recent years, particularly focusing on implementation practice. Even the best-designed services and programmes will fail if they are implemented poorly. There is growing recognition that that there is an implementation gap between what is known about effective services and how they are developed and delivered in practice.[51] This is not a top-down process, however- it is informed by practice experience on the ground so documenting and exploring 'what works' for practitioners and service users also makes a major 'bottom up' contribution to implementation practice.[52]

Effective implementation tools

153. As countries in the Region are at different stages in their deinstitutionalization journey and in order to support the 'how' as well as the 'what' of the strategy, two particular tools have been selected in this guidance to support implementation. Firstly, The Hexagon model developed by the National Implementation Research Centre (NIRN)[53] at Chapel Hill in North Carolina can be used at any stage in a project or programme's implementation to determine its fit with the local context. It is most commonly used during the early exploration stage - the period when possible new projects, policies or practices are being identified for implementation. If the organization has an Implementation Team, the Implementation Team can carry out this function for the organization. This work is particularly important at the stage of project planning in identifying whether enough of the relevant conditions are met to support implementing a particular project or programme at a point in time. A simplified version of the Hexagon tool is provided at **Appendix 7**. A full version can be found at https://implementation.fpg.unc.edu/resources/hexagon-exploration-tool and could fit well with the use of the LeBlanc model described earlier.

154. The second model is the **Outcomes-based Accountability model (OBA)** developed by Mark Friedmann[54] which has been used in the USA, the UK and several other countries worldwide as a way of structuring planning to improve outcomes for whole populations and for service development an improvement. The OBA approach focuses on the outcomes that are desired and the monitoring and evidencing of progress towards those desired outcomes. Key features of OBA include:

- population accountability, which is about improving outcomes for a particular population within a defined geographical area
- performance accountability, which is about the performance of a service and improving outcomes for a defined group of service users

These features make it well-suited to selecting children with disabilities as a target population.

[51] Fixsen, D. et al, Ibid.

[52] Fixsen, D. et al. Ibid

[53] Metz, A. & Louison, L. (2018) The Hexagon Tool: Exploring Context. Chapel Hill, NC: National Implementation Research Network, Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill. Based on Kiser, Zabel, Zachik, & Smith (2007) and Blase, Kiser & Van Dyke (2013).

[54] Friedman, M. (2005) Trying Hard is Not Good Enough. Trafford Publishing

155. Another key feature of OBA is the use of performance management categories which distinguish between 'How much did we do?', 'How well did we do it?' and, the most important category, 'Is anyone better off?' A worked example for deinstitutionalizing children with disabilities under three is provided at **Appendix 6**. A detailed guide to OBA is provided at http://raguide.org. The following sections set out the core elements of the tools.

The action plan

156. When the goal, indicators, baselines, drivers, partnerships, evidence about what works, funding and power to make change are in place, the strategy and plan can be drawn up. The deinstitutionalization plan needs to be multi-agency, multi-systemic and multi-year with an identified budget and clarity on deliverable actions, responsibilities and timescales. Each action must be able to be linked to reducing numbers in institutions, with a clear priority on the youngest and most vulnerable children; for example, a target about developing early diagnosis and intervention centres will be linked to reducing numbers of children with disabilities in baby houses over a realistic timescale, regardless of whether different Ministries are responsible for those two services. (See the earlier discussions on partnerships.)

157. The key characteristics of a good plan are as follows:

- A single, clearly defined measurable outcome, underpinned by short, medium- and long-term objectives
- Realistic timescales.
- It is informed by the past but focused on the future.
- Takes into account external factors and constraints.
- The tasks in the plan all contribute to the same objective.
- The plan does not include anything unnecessary for the achievement of the objective.
- The plan is sufficiently detailed for its purpose.
- Responsibility for who does what is clear.
- The measures in the plan are clearly aligned to success.
- The plan is revisited and updated at appropriate intervals
- A communication plan is in place to share progress and maintain support from all stakeholders and wider public

The key performance measures of progress will be built into the action plan in order to answer the questions How much did we do? How well did we do it? Is anyone better off?

The essential components of implementation

158. As the Bronfenbrenner model shows, successful and sustainable implementation of innovations always requires organizational change at multiple levels. The essential implementation components are:

- changes in adult professional behaviour, (knowledge and skills of practitioners and other key staff members in an organisation or system)
- changes in organisational structures or cultures, formal or informal, (values, philosophies, ethics, cultures, procedures, decision-making) routinely to bring about and support the changes in adult professional behaviour, and
- changes in relationships to consumers, stakeholders, (location and nature of engagement, inclusion, satisfaction) and systems partners
- developing an understanding of costs and outcomes

Evidence

159. Evidence is about what it would take to turn the baseline curve - what are the best practices in the field of prevention and deinstitutionalization, what is known about what works from research and practice, both in terms of the identifying services needed to support children with disabilities outside institutions and in terms of developing the services? The criteria for these decisions could include:

- Specificity - can it be done? Who, what, when, where, how? What can be learned from other countries?
- Values- are these actions and new supports and services consistent with the principles and values of deinstitutionalization such as the priority for family-based care and the values of the community (see communication and public awareness above)

Feasibility

160. There are a number of elements to feasibility - is deinstitutionalization actually deliverable in the current context? These include the power to deliver the changes and finance and funding but must take account of the issue of implementing the ideal solutions in less than ideal conditions. Use of the hexagon model can be used to identify the core areas which have to be aligned for the implementation of the changes to be effective. They will also identify where more work needs to be done in a particular area before proper implementation can start. The areas are:

- Capacity to implement
- Fit with current initiatives
- Need
- Evidence to support the changes
- Usability
- Supports- staffing, data systems etc

Power

161. The owners/signatories of the plan must have the power to deliver the necessary changes within their own sector, whether legislative, policy, structural, financial, service or professional practice and that also includes the power to tackle the inertia which too often derails major structural changes. Whatever plans are put in place at a high level, on the ground people like to continue to do what they have always done because it is within their comfort zone. Therefore, each organisation involved in the deinstitutionalization process needs to deconstruct the plan down to its own front-line staff, taking account of the likelihood of resistance and identifying measures to overcome it.

Finance

162. The move from institutions to community-based services requires structural changes to the finance systems at national and local level. This has to be Finance Ministry-led and set up as a rolling programme which is adapted/amended each year to take account of the changing ratio of institutional to community provision and managed across the sectors of health, education and social care/ social protection. For example, in the Republic of North Macedonia, the national finances are not constructed in such a way as to make it possible for funds obtained from the sale of an institution and its land to be ring-fenced for alternative services because the Government only has one budget pot into which all income from every source goes. The result of this is that, in spite of a relatively successful deinstitutionalization process, the Ministry responsible for the institutions is not closing them but is allowing smaller institutions, such as assisted living units for adults, within them. This means that funding is still locked into institutions while family and community- based resources such as social work, early intervention and foster care remain under-developed.

163. Mansell et al[55] also point out that centralised budgets may be better vehicles for implementing national policies or priorities, but devolved budgets make it easier for local needs and preferences to shape local services. In turn this could make it easier to alter the balance of care away from institutionally oriented services and in favour of community care. This reinforces the need for effective partnerships between central and local government and services to identify the appropriate balance between central and local planning.

164. In Belarus there are plans for the implementation of per capita budgeting as a means of improving support to children with disabilities. It began in secondary education and is being expanded. In 2019 it will be used across two regions and one of the outputs of the pilot will be recommended staffing levels in education settings, based on local conditions. The current staffing systems are centrally driven and very inflexible, making it difficult to build services around an individual child or group of children which creates a major barrier to inclusion of children with disabilities at local level.

165. However, in some countries in the region, local government structures and power are very limited and little is devolved at local level (also affecting the development of social work services) and this has to be addressed in considering the context for change.

[55] Mansell et al. (2007) op.cit

166. In the Republic of North Macedonia, in spite of a major deinstitutionalization plan being implemented and a policy shift to community-based services, the failure to enshrine long term funding through structural financial reform is preventing the third sector from coming forward to develop local services for adults with disabilities as they have no guarantee of long-term sustainable funding for service users.

167. Funding levels must include the finance necessary to support double-funding of current provision while new community-based resources such as foster care and early intervention centres are developed and practitioners appropriately trained. Account must also be taken of the long-term and changing needs of the population being served- for example if children are de-institutionalized and receive education, they are likely to want to live in local communities and join the workforce as young adults rather than 'graduating 'to the adult institution. These changes must be anticipated as part of a lifecycle approach.

Addressing transitions

168. Previous sections of this guidance have emphasised the importance of using the best available data about the children, where they or their families live and availability of current services to plan reforms including the priorities, sequencing of changes and the transition period. This is to ensure that there is the appropriate range and balance of provision available to meet identified need in the shorter and longer term.

169. For children under 10, family-based care will always be a priority and there are no circumstances in which it is acceptable to place a child under 3 in a large institution and few for those under 10. The fact that so many very young children with disabilities under 3 remain in institutions in the region means this is the key target group. Closing baby houses, which are usually well-staffed will release funding for reinvestment. The baby house in Belarus run along strongly medical model lines, also served as a palliative care unit for children with life limiting illnesses, which was clearly its own priority. It could develop this function as an outreach service for parents of other severely disabled children and deliver a much- needed shared care/respite service, while closing the baby home where there was evidence of unkindness and which could not meet the needs of the very young children with disabilities living there.

170. Managing transitions during the time of change is particularly challenging in the field of social welfare. For those older children already in institutions, a move to smaller SGHs or smaller units may be beneficial and for many of those children and young people it need only be on a temporary basis, helping the children to adapt to non-institutional settings. As set out in discussions about the role of SGHs, the role of the home can include developing the skills for family life with normative expectations of behaviour, access to signing and other means of communication. This also includes appropriate and evidence-based purposeful work to improve all areas of development, with a particular focus on participation, choice and agency.

171. Within institutions there are low cost changes which can be made in these areas as part of the preparation for deinstitutionalization - children having their own clothes, choice over activities, improved communication aids to articulate wishes and feelings and greater outreach work with parents and potential foster carers which can prepare children for family life in the community. Using frameworks to assess suitability of individual institutions and boarding schools will help with decision-making about what is so bad that immediate investment must be made in short-term alternatives, even if costly, as the environment and care are so unsuitable, or where some improvements could be made to make it 'good enough' while longer term resources are developed. This analysis also applies to considerations about whether a return home will offer 'good enough' care for the child, while community-based services are being developed.

172. In the countries visited there was little discussion of kinship care as an option for children though it is much used elsewhere. These carers seem to be excluded from policy debates and services are developed with little attention to the role that kinship carers might play. This is a key resource which could be developed relatively quickly as a family- based setting for children to prevent entry to and support exit from institutions though is again dependent on the availability of community-based services.

173. If priorities are set in the deinstitutionalization plan and family- based services developed whether birth, wider family or alternative care, then the throughput from small group homes will increase, thus reducing the costs. However, at the heart of the process, families will only care for their children if they have a meaningful relationship with them and that must be encouraged, developed and supported regardless of the setting.

174. An important caveat which has been highlighted in a report on deinstitutionalization in the Republic of North Macedonia[56] is that *'the deinstitutionalization processes and development of child welfare services still appear to be built on the premise that all cases will arrive from families with insufficient income, material poverty or disability. The problems of violence, abuse and exploitation that harm children do not yet seem to have been detected on the social services radar. There are dangers of not working to develop a child protection service that deals with these issues.'*

175. Given that worldwide it is known that children with disabilities are more likely to experience all forms of abuse and neglect in families, communities and institutions, this awareness must be built in to the assessment and planning systems and particularly for the workforce across sectors.

Monitoring and evaluation of the change programme

176. Using the tools provided through the Hexagon model, OBA and the Nexus model to identify synergies along with the risk registers, steering groups and subgroups will enable a robust strategy to be developed and delivered. The tools will help to identify the KPIs, monitor the alignment of partners and identify where changes need to be made in the light of developments as the programme develops.

Summary

- There is growing recognition that there is an implementation gap between what is known about effective services and how they are developed and delivered in practice which has a major impact on the capacity to deliver change in complex projects and programmes

- Two tools with a strong evidence-base are proposed to support implementation of deinstitutionalization- Outcomes-based Accountability (OBA) and the Hexagon Tool which provide a systematic approach to planning, implementing and monitoring change processes for particular target groups and delivery contexts from identifying target groups and partnerships and the baseline data to the performance indicators for monitoring

- Deinstitutionalization programmes are multi-year projects and flexible finance systems at local and national level are key to achieving sustainable change over time. This includes the ability to shift money between budgets and adjusting budgets in line with the changing priorities and balance of provision

- Kinship care which is well supported can provide an important community-based resource for children and families and can be developed within short timeframes to boost deinstitutionalization

- Assessments of child-centred quality of care will provide evidence about priorities for closure and the appropriateness of alternative provision to meet children's developmental needs

[56] Dunn, A. (2018). Deinstitutionalisation and the development of child protection and family based alternative care services for children. UNICEF

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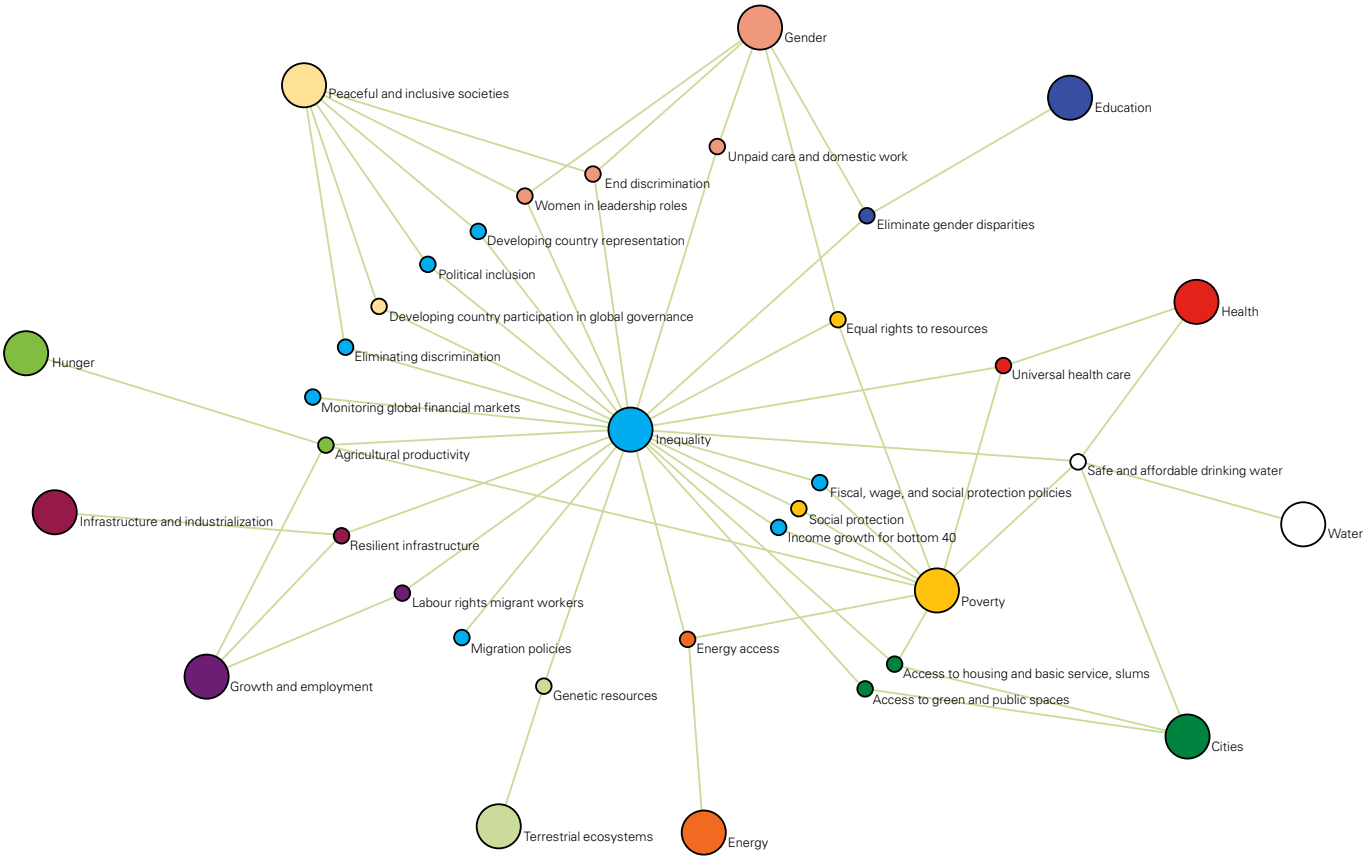
THE TOOLKIT

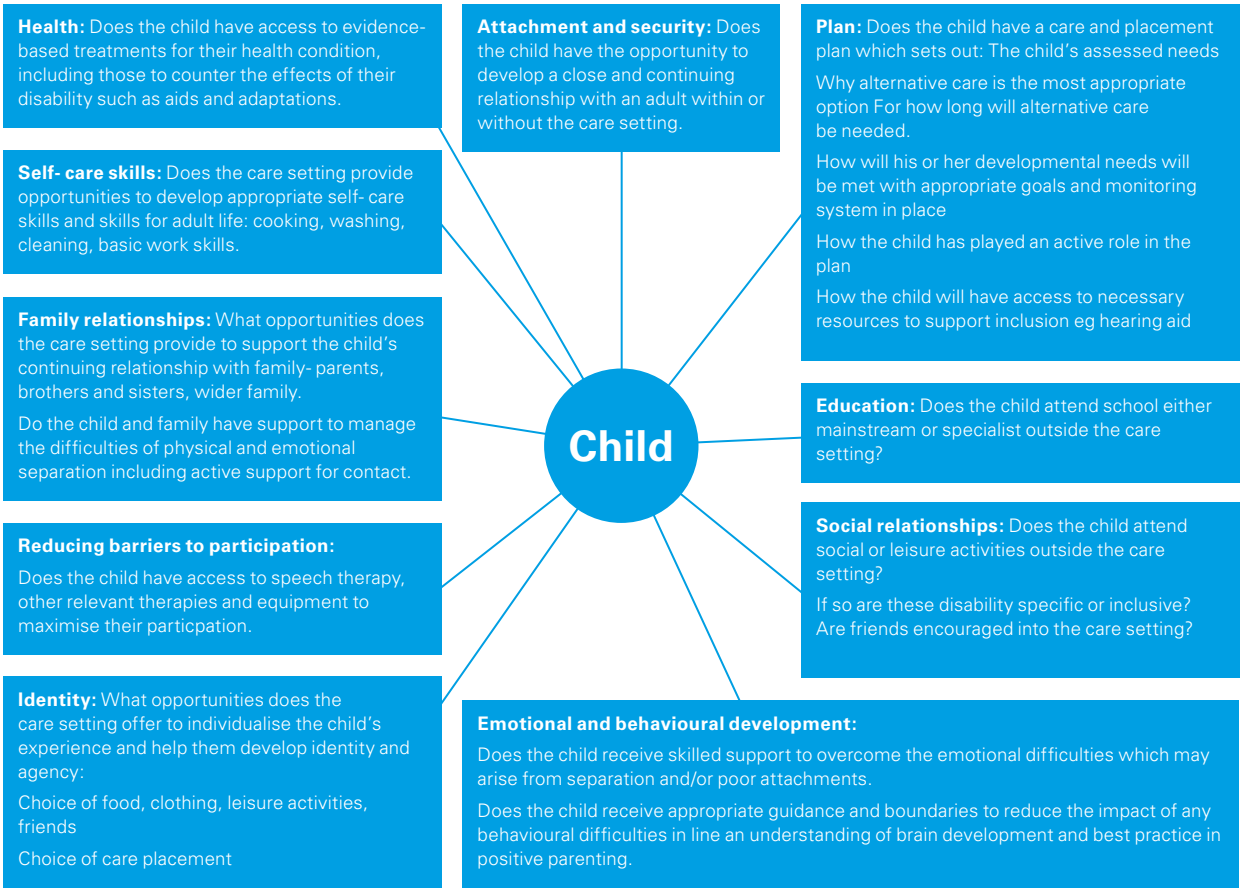
APPENDIX 1: EXAMPLE OF A NEXUS: LINKS AMONG SDG 10 (INEQUALITY) AND OTHER GOALS



APPENDIX 2: THE FAMILY WELLNESS SERVICE CONFIGURATION MODEL

	Child	Family	Community	Society
Universal	Universal Child Health screening Immunisation programmes	Home visiting for parents of new born children Parenting programmes	Public education campaigns on disability awareness Inclusive schools and playgroups	Family allowance payments for each child to parents
Targeted	Participation groups for children with disabilities	Training for foster carers Support groups for parents of children with disabilities	Lowered pavements Accessibility of buildings and transport for a range of disabilities	Payments and allowances for children with disabilities
Specialist	Individualised physiotherapy Technology-based communication aids	Parenting programmes for children with ASD	Early intervention centres	Local and national protocols for multiagency working with children with disabilities

APPENDIX 3: SUITABILITY OF CARE SETTING FRAMEWORK



APPENDIX 4: A WORKED EXAMPLE OF AN ASSESSMENT OF AN INSTITUTION USING THE SUITABILITY MODEL

INSTITUTION A

Attachment

- There are no opportunities for developing an attachment to anyone inside or outside the institution
- Lots of affection between staff and children but very generalised rather than individualised
- Only 20 children out of 260 have regular contact with a family member
- Only 50 more have any contact

Health

- There is access to basic healthcare in the institution but not to specialist treatments; they have basic medication but cannot afford more specialist medication for which they are dependent on donors and if the child is hospitalised the institution has to pay for basic hospital care such as cleaning which parents would otherwise do
- Most basic wheelchairs available but no other mobility enabling equipment evident (the institution was undergoing major renovation so not everything was on show)

Reducing barriers to participation

- Speech therapy said to be available (not sure how much) but little evidence of staff encouraging speech in daily interaction and there was no use of sign language
- No other computer-based work with communication aids seen
- A few groups doing reading and writing

Self- care skills

- Little to no opportunity to develop basic self-care skills
- No choice about clothing- everything communal and decided by staff
- No participation in food preparation or choice of food
- No choice over sleeping arrangements
- Will move from children's institution to adult institution so no need?

Family relationships

- Little opportunity to work with parents as most not in contact- many parents are working abroad or can't be found- though this was seen as something which needs to be done
- Director and deputy viewed parents rather negatively- say that children come back from home visits dirty and uncared for, that parents don't know how to or don't want to care
- Recognition of how the children long for their family (however bad) and that it's where they want to be but there was no sense of active support for contact or recognition of difficulties on both sides

Identity

- Almost no opportunity for child to develop sense of identity- they were treated as part of a herd; at one point sweets were handed out and the children gathered around like ducklings being fed
- No choice or control over daily life- clothes, food, friendship
- No individuation or privacy- even the new toilets were arranged in open groups of three
- No choice of care placement
- Impact of lack of speech or other form of communication in expressing wishes and feelings and in identity formation
- Identity formation was not seen as a goal

Emotional and behavioural development

- No evidence of work with the child to overcome impact of loss though recognition that it's there
- Little evidence of guidance and boundaries children rush around, in a group with no expectations of normal/normative behaviour
- In newly renovated building there were bars on the windows to protect the children rather than teaching them safety
- No use of evidence-based practices, no positive parenting techniques again linked to lack of individuation

Social relationships

- No interaction with local community seen or discussed but visits outside the home to events etc and holiday centre talked about. Children spend time out of the home on activities but not in any integrated way so no access to positive role models
- No children from outside come to play

Education

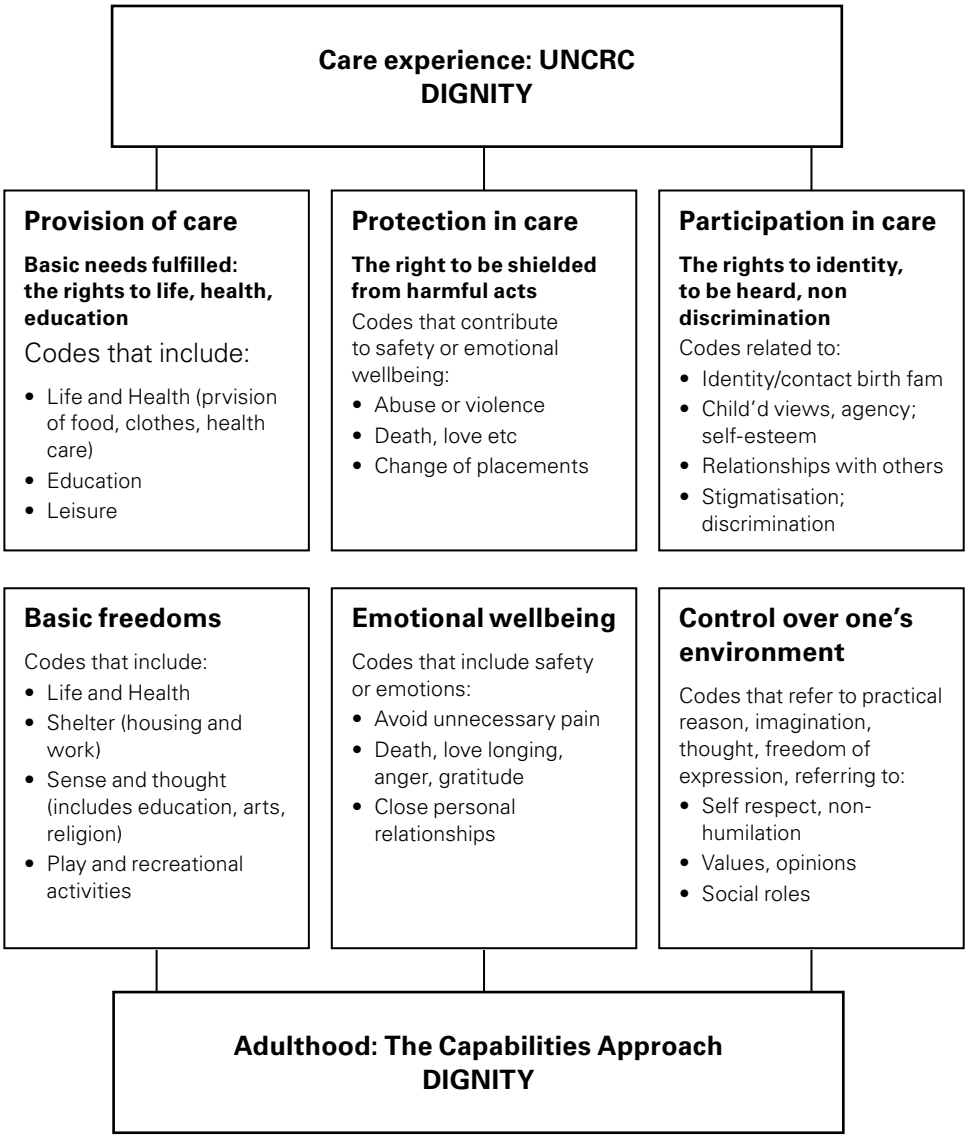
- No child goes to a school outside the home—the majority of the children have significant intellectual difficulties but there are efforts to teach some of them basic reading and writing
- All children have some form of education though for the most disabled children (of whom there are many) it comes in the form of stimulation including physical stimulation massage

Plan

- There was no evidence of assessments of progress or an individualised plan though there is a daily plan for physical handling of the most disabled children (bed or chair ridden) in terms of how often to be moved and into which positions
- The view is that parents don't want them, they won't be going home and will 'graduate' to adult institution

These factors can be weighted in identifying suitability which is important when considering how to manage transitions from institutions where alternative resources are undeveloped.

APPENDIX 5: THE DIGNITY APPROACH TO CARE



APPENDIX 6: A SIMPLIFIED VERSION OF OUTCOMES-BASED ACCOUNTABILITY FRAMEWORK

Population Accountability

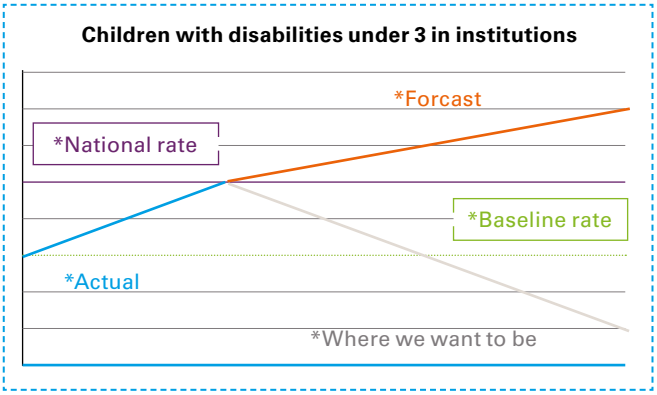
Population: Children with disabilities

Outcomes: Children with disabilities are able to live in families and communities

Indicators:

- Numbers of children with disabilities living at home or with wider family and friends as a % of all disabled children
- Numbers of children with disabilities living in group care of more than 12 children as a % of all disabled children
- Numbers of children with disabilities living in group care of less than 12 children as a % of all disabled children
- Numbers of children with disabilities living in foster care as a % of all disabled children

Baselines for each indicator: Show history and forecast on current effort level (where we have been, where we are headed).



For each indicator show:

The story behind the baseline:

- What are the reasons behind this
- Other forces at work
- (for local completion) Partners with a role to play:
- (for local completion) What works:

What do we know that has been shown to work:

- Research
- Best practice
- Innovation and creativity
- What could we implement now including no cost and low cost ideas

Action plan: Who (action by different partners), what, budget → commissioning

APPENDIX 7: THE HEXAGON TOOL

The Hexagon: An Exploration Tool

The Hexagon can be used as a planning tool to guide selection and evaluate potential programs and practices for use.

IMPLEMENTING SITE INDICATORS

CAPACITY TO IMPLEMENT

Staff meet minimum qualifications

Able to sustain staffing, coaching, training, data systems, performance assessment, and administration

- Financial capacity
- Stuctural capacity
- Cultural responsivity capacity

Buy-in process operationalized

- Practitioners
- Families

FIT WITH CURRENT INITIATIVES

Alignment with community, regional, state priorities

Fit with family and community values, culture and history

Impact on other interventions & Initiatives

Alignment with organizational structure

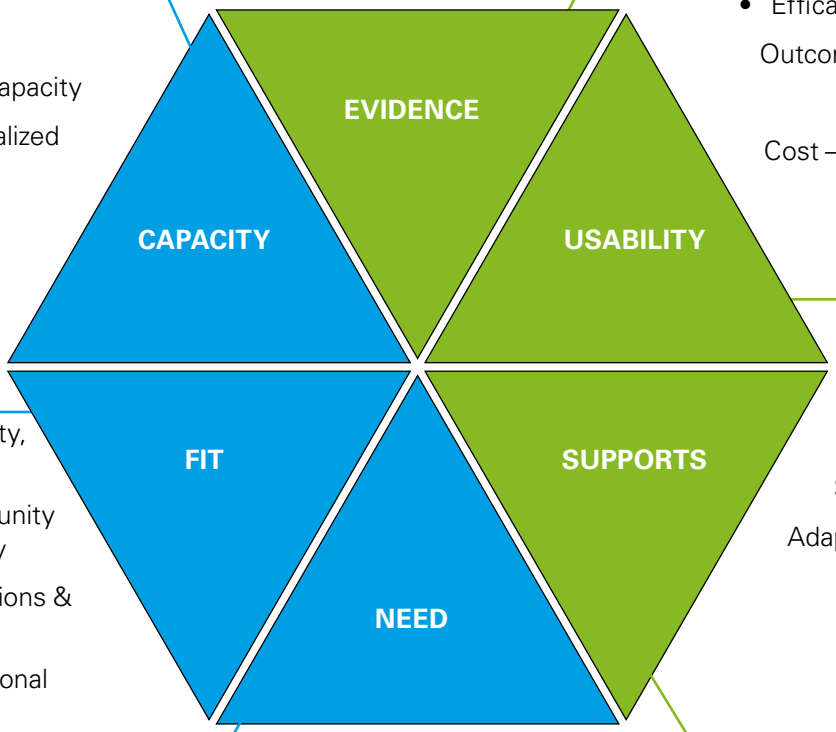
NEED

Target population identified

Disaggregated data indicating population needs

Parent & community perceptions of need

Addresses service or system gaps



PROGRAM INDICATORS

EVIDENCE

Strength of evidence–for whom in what conditions:

- Number of studies
- Population similarities
- Diverse cultural groups
- Efficacy or Effectiveness

Outcomes – Is it worth it?

Fidelity data

Cost – effectiveness data

USABILITY

Well-defined program

Mature sites to observe

Several replications

Adaptations for context

SUPPORTS

Expert assistance

Staffing

Training

Coaching

Racial equity impact assessment

Data Systems Technology Supports (IT)

Administration & System

Appendix 8: Core elements of the needs analysis

Needs analysis model

What is a needs analysis?

A needs analysis provides a rationale for current and future services. It involves understanding as fully as possible:

- the profile and needs of the population that your organisation serves
- the range of services already available to meet those needs
- how much these services cost and how effective they are
- where the gaps are
- the consequences of not addressing the gaps
- how any new service will fit with existing ones

What will the needs analysis help you to decide?

When you have made an assessment of the current situation (demographics, services, outcomes, costs etc), the needs analysis should help you to identify any unmet needs and gaps in provision. This will then help you to think about:

- what you might need to do differently?
- what you can afford to do /not do?
- what you need to do to match needs with capacity?

Any recommendations you make should be underpinned by:

- a clear statement of priorities
- an assessment of intended service quality and outcomes
- an assessment of intended cost effectiveness/ value for money
- baselines for outcomes measurement

Leadership and management

It is important that the needs analysis process is properly led and managed, and that roles and responsibilities are clearly defined and understood.

Ownership of the process should reside with the steering group, whose responsibilities will also include:

- ensuring that the needs analysis is seen as an ongoing part of the whole project
- engaging the support of partners across the programme
- disseminating the findings to partners to inform wider commissioning and/or decommissioning of services

As well as ensuring that a coherent needs analysis document is produced on time, the responsibilities of the **project leader(s)** will include:

- scoping/defining the parameters of the process
- co-ordinating partnership working

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