

The Care Force Planning Cycle—Step 1
Care force profiling & analysis

Demography of the family careforce

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Outline

Background

- ▶ Changes in the demography of children and families affected by HIV and AIDS

Counting the family careforce

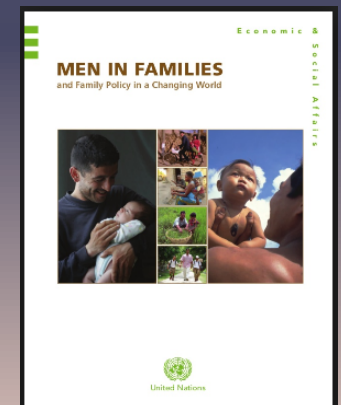
1. Who is in the family careforce?
2. Where are the family careforce located?
3. What data are available?

Recommendations

Conclusion

Building on joint learning about families affected by HIV

- ▶ Concepts, measures and methods can heighten the ‘invisibility’ of some family members and carers
- ▶ Care roles and responsibilities within a family may be complex and dynamic
- ▶ Families and households are shaped by a range of processes, not only HIV



Population and family changes

- ▶ Many influences shape the composition and functioning of families
 - ▶ Marriage, child bearing and cohabitation
 - ▶ Housing, land
 - ▶ Migration and urbanisation
 - ▶ Livelihoods, labour markets, female breadwinners
 - ▶ Education, adult transitions
 - ▶ Cultural and social norms
 - ▶ Gender norms, autonomy of men and women
 - ▶ Statutory and civil organisation service provision

Changing profile of children affected by HIV

- ▶ Public HIV treatment and care > 11 million people
- ▶ Increasing life expectancy of HIV-infected children and adults
- ▶ Decreasing mother-to-child transmission of HIV
- ▶ Decreasing orphaning prevalence of children due to HIV
- ▶ Increasing community-level HIV prevalence
- ▶ Increasing HIV prevalence in adolescents and young adults

- ▶ What is the impact on the profile of children and adolescents affected by HIV?

Who is in the family careforce?

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It is the ~~adults~~ person or people who ~~could care for~~ ~~are willing to~~ care for a child by ~~providing~~ ~~being responsible for~~ being positively involved ~~financial material~~ ~~emotional~~ in ~~any way~~ meeting his or her ~~basic~~ needs.

Who is in the family careforce?

- ▶ 'Force' - one or more people providing care – *group, shared care*
- ▶ Is the family careforce specific to each child of interest?
- ▶ What types of caregiving matter?
- ▶ Are the carerforce those actively involved in care?
- ▶ Need the family careforce conform to statutory or legal criteria for carers of children?
- ▶ Irrespective of a carers' specific circumstances?

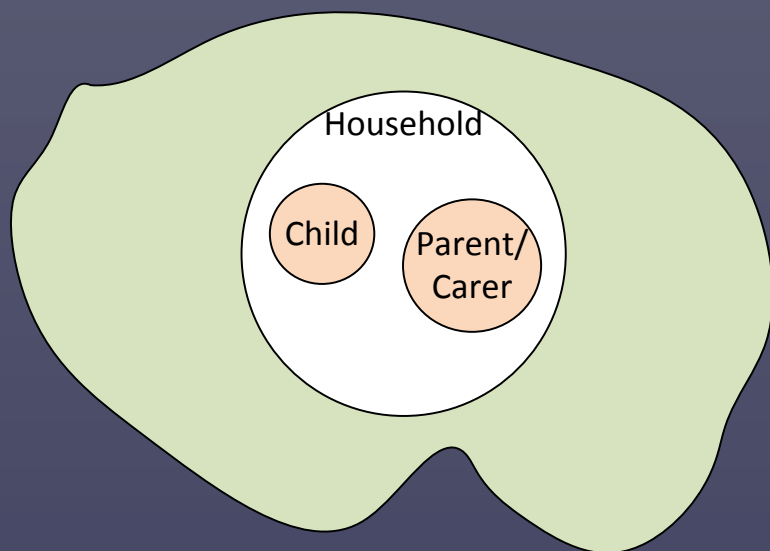
Who is in the family careforce?

- ▶ Profiling and analysing the family careforce – with what purpose?
 1. Statistics, research and planning
 2. Family-centred support programmes
 3. Monitoring and evaluation of family programmes and policies

Where are the family careforce located?

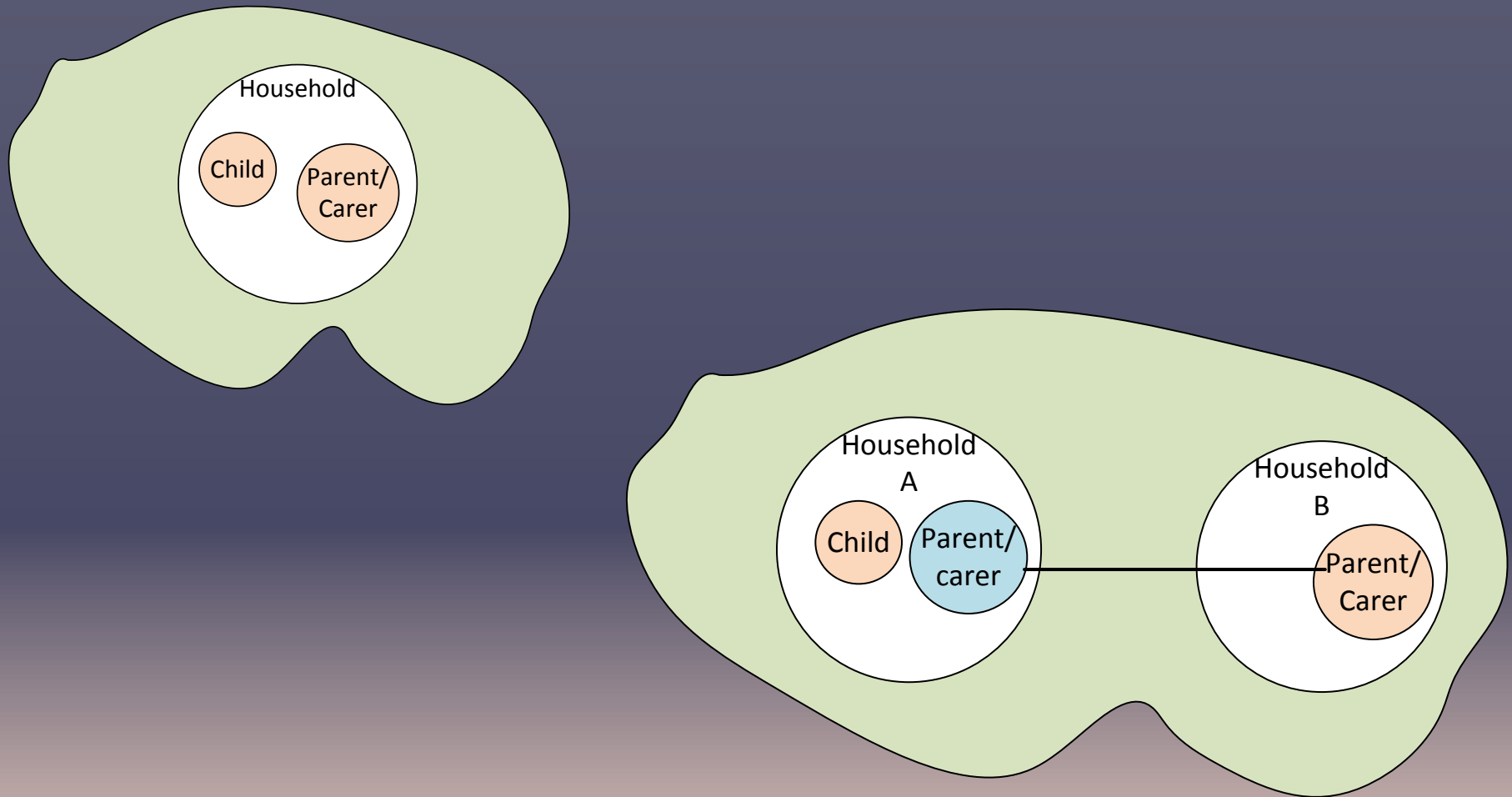
Where are the family careforce located?

- ▶ Must family carers live together with a child?



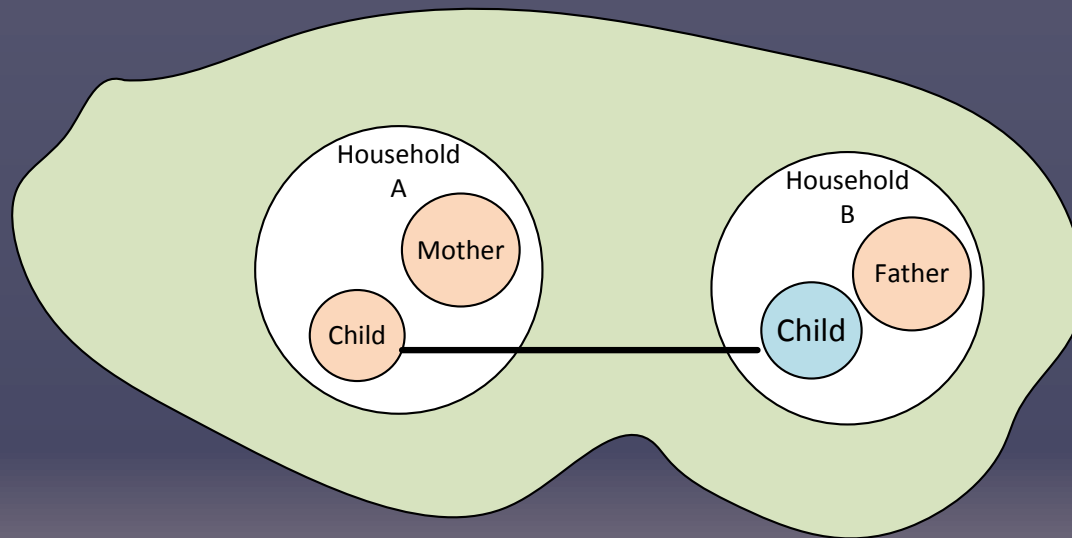
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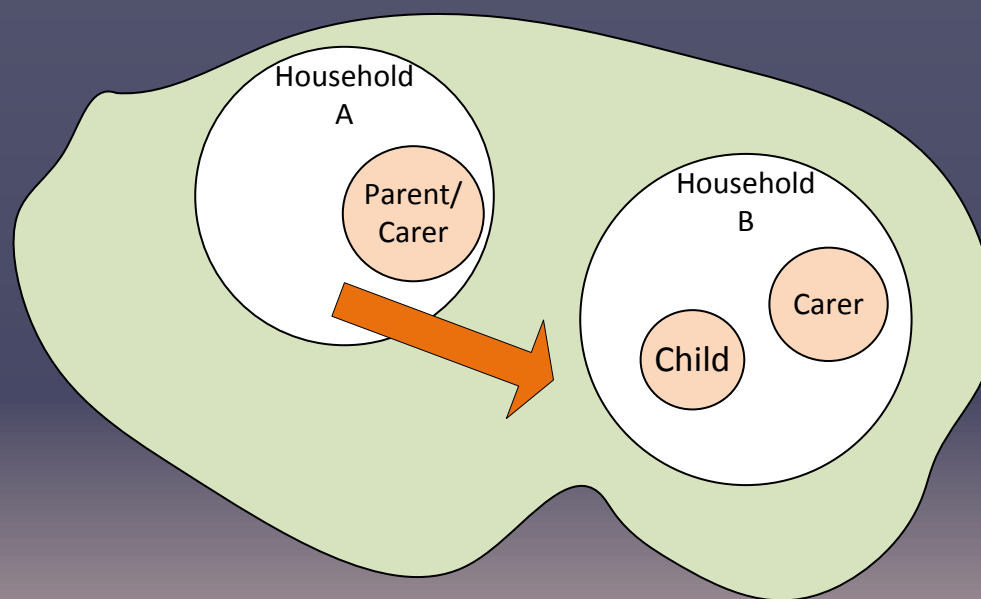
Where are the family careforce located?

- ▶ Must family carers live together with a child?
- ▶ What if the child belongs to more than one household?



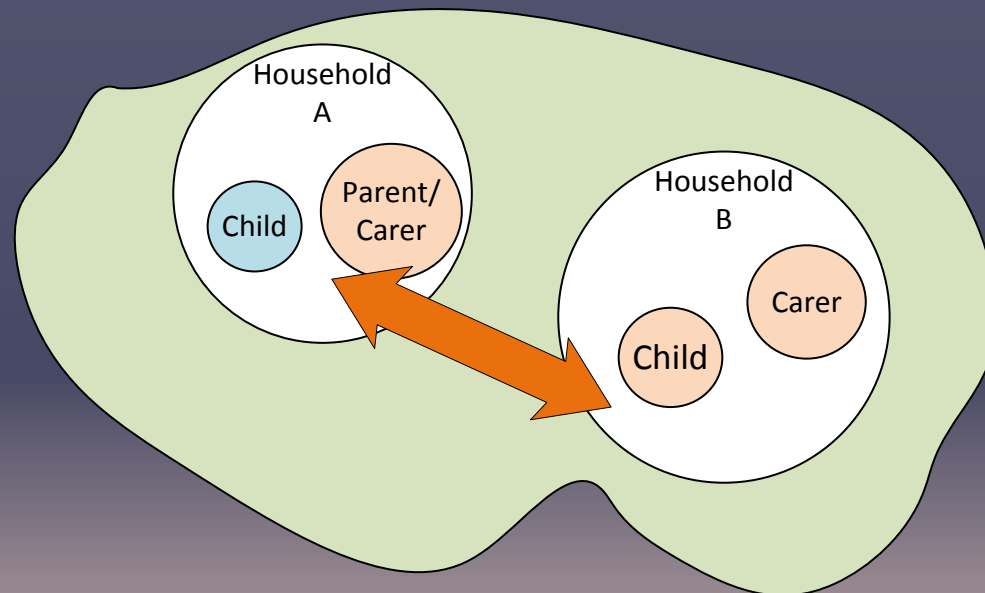
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- ▶ Must family carers live together with a child?
- ▶ What if the child belongs to more than one household?
- ▶ What if the child migrates?



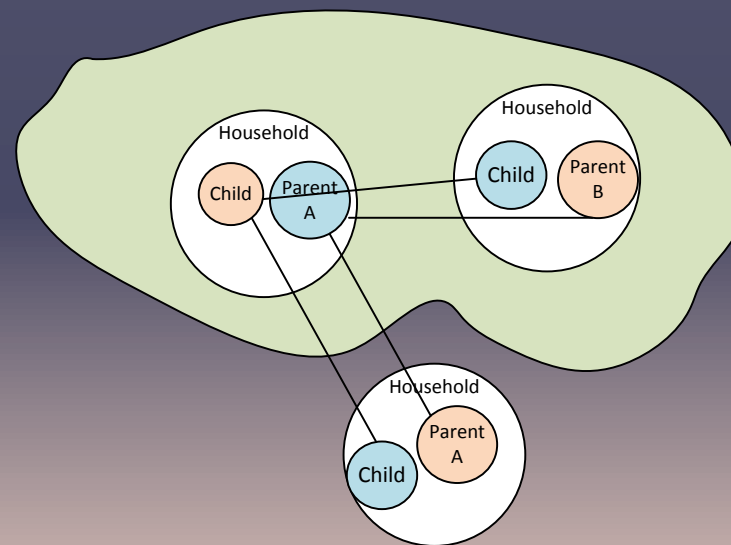
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- ▶ What if the child belongs to more than one household?
- ▶ What if the child migrates? And returns again?



Where are the family careforce located?

- ▶ Must family carers live together with a child?
- ▶ What if the child belongs to more than one household?
- ▶ What if the child migrates?
- ▶ How do we support children and carers in dispersed family arrangements?



What data are needed to profile
the family careforce?

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- ▶ Profiling and analysing the family careforce – with what purpose?
 1. Statistics, research and planning
 2. For family-centred support programmes
 3. M&E of family programmes and policies

Data for statistics and research

Censuses and household surveys

National HIV surveys
Population-based surveillance

Cohort studies

Smaller focused studies using a mixture of methods

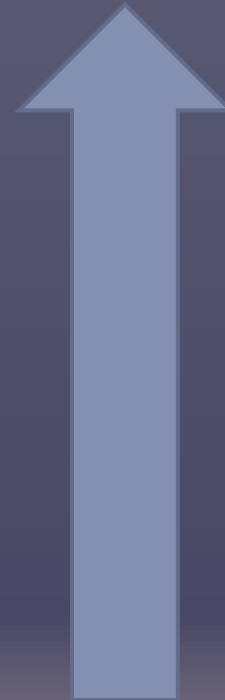
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Less detailed information on family relationships, functioning, care needs, care provision, social protection

Data for family support programmes

- ▶ Reliable data on individuals
- ▶ Up to date, complete
- ▶ M&E pre- and post-intervention

- ▶ **Targeting**
- ▶ Case finding and notification
- ▶ Administrative data

- ▶ HIV treatment services as points of entry for data collection and provision of family-centred support

Recommendations

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I. Researchers and practitioners should advocate for greater access to, and linkage of, administrative data at national, regional and local levels



Recommendations

2. Migration, mobility and family dispersal need to be considered at all stages of research, intervention and policy development and evaluation



Recommendations

3. Research and programmes should give greater attention to identifying the group of family carers and how best to engage with all of them



Recommendations

4. Continuous efforts needed to reach children and adults who are not in HIV treatment and care are needed in addition to those already in HIV treatment services



Conclusion