

## Introduction

Should children living with HIV/ AIDS (CLHA) receive family and community-based care or institutional care? Is it more humane and more financially efficient to care for acutely vulnerable children “at home” or “in a home”? Should we be focusing on “building families” rather than building institutions? Which of the models of care should donors prioritize when making decisions about funding?

The present paper seeks not so much to answer the above questions as to challenge the thinking behind them.

Underlying the pitting of institutional care against the “alternatives” of family and community-based care is the not-implicit assumption that the two are mutually exclusive, that one precludes the other: that institutions weaken familial and community ties, that funding institutional care drains resources from community-based initiatives.

This paper problematizes such binary thinking through a case study of Sneha Care Home (SCH) – a care centre for CLHA which blends family and community-based initiatives with institutional care.

The paper is divided into two parts.

Part one sets the context and analyses the prevailing discourse surrounding the long-term care of vulnerable children. It begins by offering a cursory overview of a number of key policy documents dealing with the issue of vulnerable children’s long-term institutional care: the overwhelming majority of which endorse a shift from institutional care to the “alternatives” of family and community-based care. Next, the assumptions underlying this “alternatives agenda” are highlighted and critically evaluated. Attention is drawn to the discrepancy in the language used - and the policies developed - in relation to private boarding schools on the one hand and institutional care on the other.

The overall argument made in part one is that, for a number of reasons, the proposed “alternatives” of family-based and community-based care cannot be considered adequate replacements for institutional care.

The second part of the paper is a case study of SCH with a particular focus on the procedures it has adopted to blend institutional care with family and community-based initiatives. The proposition made through the case of SCH is that dichotomies such as “at home or in a home” and “build families not orphanages” become difficult to sustain when institutions trace children’s family members, extend support to surviving parents through a “Keep the Parents Alive” policy and when ensuring regular and sustained contact between the child and family is part of the job description of two of the institution’s staff members. Similarly, the boundaries between institutional care and community-based care are somewhat blurred when community-based organisations become “extended arms” of institutions, when institutions spearhead community-based initiatives.

The paper is not meant to serve as a “best-practice” guide – longitudinal studies would still be needed to assess the extent of such a model’s success. Moreover, its primary aim is not to critique SCH processes - though description does give way to analysis at various points. Instead the purpose is to use the case study of SCH as a catalyst for thinking beyond the “either-or” model (that is, “either” institutional care, “or” family and community-based care) and to take seriously the possibility of blended models of care.

In the process it hopes to show that “building families” may not require demolishing institutions – only thinking more creatively about how they are run.

## PART I

### 1

#### Language of policymakers

#### The “Alternatives” Agenda

Long-term institutional care does not occupy a particularly favourable position on national and international healthcare policymakers’ agendas right now. In their various criticisms of institutions: too expensive, too soulless, too cut-off, too dehumanizing - policymakers have found strong allies in a growing number of NGOs, children’s rights groups, social workers and academics. From one policy document to another, one advocacy paper to another, the mantra has increasingly become that of “alternatives” to institutional care: of “permanency planning”, “family-based” or “community-based” care as cheaper, more effective, more compassionate and less segregating models of care.

The mantra has been applied to Homes for the elderly, persons with a disability as well as adolescents with behavioural difficulties. Yet as this paper focuses on the care of CLHA, the emphasis here is on documents that deal with the issue of institutional care for vulnerable children in particular. And it is here that the anti-institutional mantra is perhaps strongest.

The reasons for this shift from seeing institutions as a quite revolutionary model that provided a home for the dispossessed – as “saving” children who would have otherwise been left to fend for themselves - as they were seen in the eighteenth century<sup>1</sup> – to institutions as damaging places where children are “abandoned” and uncared for - are debatable. One argument is that the thinking emerged at a particular historical juncture, when the “unprecedented economic growth in the aftermath of World War II; governments’ subsequent disenchantment with Keynesian economic management and the supposed threat from what has sometimes been termed the demographic ‘time bomb’ of ageing” made policymakers eager to seek alternative modes of care.<sup>2</sup>

And just as demographic ageing provided catalysts for new modes of thinking about institutional care for the elderly, the threat of an increase in children needing long-term care as a result of everything from climate change and, most pertinently for this discussion, the growing HIV/ AIDS pandemic, has pushed the issue of “alternative care” high on the agenda for children too.<sup>3</sup> At a time of enormous economic strain, when concerns over public

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<sup>1</sup> Weisman, Mary-Lou (1994) ‘When Parents are not in the best interests of the child’ [The Atlantic Online] Available at: <http://www.theatlantic.com/past/docs/issues/96apr/orphan/weisorp.htm>

<sup>2</sup> Horden, Peregrine and Smith, Richard (2007) Introduction to The Locus of Care: Families, Communities, Institutions and the provision of welfare since antiquity. Routledge, 2007, p.3

<sup>3</sup> Save The Children (2009). ‘Keeping Children Out of Harmful Institutions: Why we should be investing in family-based care’ [online] Available at: [http://www.savethechildren.org.uk/sites/default/files/docs/Keeping\\_Children\\_Out\\_of\\_Harmful\\_Institutions\\_Final\\_20.11.09\\_1.pdf](http://www.savethechildren.org.uk/sites/default/files/docs/Keeping_Children_Out_of_Harmful_Institutions_Final_20.11.09_1.pdf). The Save The Children Fund (2009), p. vii

spending are high, the prospect of replacing long-term institutional care with alternatives that are argued to be both three-times cheaper and more humane<sup>4</sup> is unsurprisingly popular.

Moreover, a slew of academic papers have produced a number of unhappy findings about institutionalized populations – citing evidence that they are behaviourally, emotionally and intellectually stunted compared to their non-institutionalized peers.<sup>5</sup> Heavily publicized scandals have done little to challenge the institution’s image as a breeding ground for unchecked abuse of the most vulnerable.<sup>6</sup>

The result has been a proposed “hierarchy of alternatives [to institutional care] for children.” Pride of place is reserved for living in the home of origin, followed by adoption, kinship foster care, long-term foster care in the home of a non-family member, and last, care in an institution. Small group homes which are argued to be more personal than large institutions and guardianship are included as “subalternatives.”<sup>7</sup> Aside from minor debates about the relative desirability of a few of the options, “the idea of a hierarchy is well established in the minds of child welfare practitioners and provides guidance for their decisions.”<sup>8</sup>

While it is recognized that institutional care may, sometimes, be in the best interests of some children, this is invariably presented as a last resort and “for the shortest possible duration.”<sup>9</sup> The over-all strategy remains firmly that of deinstitutionalization.<sup>10</sup> This is especially the case given the belief that “(t)he very existence of institutions encourages families to place their children into care” and uses up funding that could otherwise go to alternative care.<sup>11</sup>

Importantly, the alternatives agenda has increasingly become linked to funding. In the US, for example, “Permanency Planning” programmes – which aim to support families to care for children in their homes – have been introduced, “at least on a trial basis,” in almost every

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<sup>4</sup> Both UNICEF and Save The Children have argued that institutional care is both harmful and costs three times the amount of family and community-based care alternatives. See for example *ibid.*, p. 21 and UNICEF (2010). ‘Developing alternatives to institutional care in Montenegro’ [online] Available at: [http://www.unicef.org/montenegro/media\\_14535.html](http://www.unicef.org/montenegro/media_14535.html)

<sup>5</sup> The North American Council on Adoptable Children’s website page ‘Build Families not Orphanages’ lists a number of the most notorious as evidence of ‘The Dangers of institutionalization’ Available at: <http://www.nacac.org/policy/orphanages.html>

<sup>6</sup> For a detailed study of child abuse in India, including within institutional settings, see report produced by Ministry of Women and Child Development, Government of India: ‘Study on Child Abuse: India 2007’ [online] Available at: <http://wcd.nic.in/childabuse.pdf>. While problems of under-reporting make all abuse statistics problematic, the report highlights the large number of child abuse cases across in India in general. The report finds that physical and emotional abuse in India is most commonly perpetrated by parents, whilst children on the streets, children at work and children in institutional settings are most vulnerable to sexual abuse.

<sup>7</sup> Schurman, John R., Rzepnicki, Tina L and Littell, Julia (1994). Putting Families First: An Experiment in Family Preservation. Walter de Gruyter, Inc. New York (1994), p. 8

<sup>8</sup> *Ibid.*

<sup>9</sup> Save The Children (2009). Keeping Children Out of Harmful Institutions: Why we should be investing in family-based care [online] Available at: [http://www.savethechildren.org.uk/sites/default/files/docs/Keeping\\_Children\\_Out\\_of\\_Harmful\\_Institutions\\_Final\\_20.11.09\\_1.pdf](http://www.savethechildren.org.uk/sites/default/files/docs/Keeping_Children_Out_of_Harmful_Institutions_Final_20.11.09_1.pdf). The Save The Children Fund (2009), p. 27

<sup>10</sup> *Ibid.*

<sup>11</sup> *Ibid.*, p. 2

state.<sup>12</sup> “Reforming the child protection system became an important milestone on the path to European Union (EU) membership in the last wave of enlargement” and continues to feature prominently in accession proceedings.<sup>13</sup> Indeed, the EU has recently cut off funding for the building of new institutional care facilities for children with a disability in Serbia.<sup>14</sup> At the 2011 launch of The United Nations Children’s Fund (UNICEF)’s study ‘At Home or In a Home,’ Irish Member of European Parliament Mairead McGuinness stated that she would put “pressure on the Commission to ensure that EU funding is not being used to maintain inappropriate institutions.”<sup>15</sup> UNICEF has declared its support for programmes “including provision of information on the detrimental impact of institutional care on the young child, and education for parents of children with disabilities and parents at risk of abandoning their infants” to discourage the use of institutional care.<sup>16</sup> Save The Children (STC) encourages “[d]onors to ensure that funding is directed at preventive community and family support and at family-based alternative care.”<sup>17</sup> The list goes on.

The ubiquity of its endorsement amongst policymakers makes a critical review of the “alternatives” agenda, and the assumptions underlying it, crucial. It is to this which the paper now turns.

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<sup>12</sup> Schuerman, John R., Rzepnicki, Tina L and Littell, Julia (1994). Putting Families First: An Experiment in Family Preservation. Walter de Gruyter, Inc. New York (1994), p. 19

<sup>13</sup> UNICEF (2010). Developing alternatives to institutional care in Montenegro [online] Available at: [http://www.unicef.org/montenegro/media\\_14535.html](http://www.unicef.org/montenegro/media_14535.html)

<sup>14</sup> The International Disability and Human Rights Network (30/7/2011) Serbia: European union stops funding for institutional care [Online] Available at: <http://www.daa.org.uk/index.php?mact=Blogs,cntnt01,showentry,0&cntnt01entryid=455&cntnt01returnid=98>

<sup>15</sup> United Nations Human Rights (August 2011), Reports Highlight Need for Alternatives to Institutional Care [online] Available at: <http://www.ohchr.org/EN/NewsEvents/Pages/Reportshighlightalternativestoinstitutionalcare.aspx>

<sup>16</sup> UNICEF (2010). Developing alternatives to institutional care in Montenegro [online] Available at: [http://www.unicef.org/montenegro/media\\_14535.html](http://www.unicef.org/montenegro/media_14535.html)

<sup>17</sup> Save The Children (2009). Keeping Children Out of Harmful Institutions: Why we should be investing in family-based care [online] Available at: [http://www.savethechildren.org.uk/sites/default/files/docs/Keeping\\_Children\\_Out\\_of\\_Harmful\\_Institutions\\_Final\\_20.11.09\\_1.pdf](http://www.savethechildren.org.uk/sites/default/files/docs/Keeping_Children_Out_of_Harmful_Institutions_Final_20.11.09_1.pdf). The Save The Children Fund (2009), p. viii

## **Revisiting the Assumptions of the “Alternatives” Agenda**

The first section of this paper offered a cursory overview of a number of key international donor policy documents dealing with the issue of children’s long-term institutional care. It was noted that the documents, whether descriptive or prescriptive in nature, raised a number of arguments against the institutional care of children – strongly discouraging its use except as a last resort temporary measure within an overall strategy of deinstitutionalization. It was also noted that a number of the central arguments raised by the organizations and put forward in these documents rested on a set of assumptions which, it will be argued in this section, may be problematic, partial or potentially reconsidered.

Assumption 1: “Family” and “community-based” care on the one hand and “institutional care” on the other: two models presented as mutually exclusive.

Policymakers frequently depict options for vulnerable children’s care as a continuum – with “family” and “community-based” care on one end of the spectrum and institutional care at the other.<sup>18</sup> In between are a number of other options – including day care centres, adoption, foster care, kinship care, small group homes and child-headed households which, though considered less desirable than biological family-based care, are similarly seen as incompatible with long-term institutional care.<sup>19</sup>

They are also seen as preferable to it.

Indeed, this “care continuum” is a continuum in the sense that it presents an array of care options which fall across a spectrum but not in the sense that children are encouraged to move along it – since the goal is increasingly that of “permanency”, and within a family setting.<sup>20</sup>

Titles of a number of influential policy documents like “At Home or in a Home”<sup>21</sup> and slogans such as “Build Families not Orphanages”<sup>22</sup> offer a stark demonstration of this tendency to think of models of care in binaries.

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<sup>18</sup> Schuerman, John R., Rzepnicki, Tina L and Littell, Julia (1994). Putting Families First: An Experiment in Family Preservation. Walter de Gruyter, Inc. New York (1994), p.

<sup>19</sup> Save The Children (2009). Keeping Children out of Harmful Institutions: Why we should be investing in family-based care. The Save The Children Fund (2009) [online] Available at: [http://www.savethechildren.org.uk/sites/default/files/docs/Keeping\\_Children\\_Out\\_of\\_Harmful\\_Institutions\\_Final\\_20.11.09\\_1.pdf](http://www.savethechildren.org.uk/sites/default/files/docs/Keeping_Children_Out_of_Harmful_Institutions_Final_20.11.09_1.pdf)

<sup>20</sup> Schuerman, John R., Rzepnicki, Tina L and Littell, Julia (1994). Putting Families First: An Experiment in Family Preservation. Walter de Gruyter, Inc. New York (1994) and Barbell, Kathy and Freundlich, Madelyn (2001). Foster Care Today. Casey Family Programs, Washington DC [online] Available at: [http://www.hunter.cuny.edu/socwork/nrcfcpp/downloads/policy-issues/foster\\_care\\_today.pdf](http://www.hunter.cuny.edu/socwork/nrcfcpp/downloads/policy-issues/foster_care_today.pdf)

<sup>21</sup> UNICEF, 2010 document on alternatives to institutional care

<sup>22</sup> North American Council on Adoptable Children (NACAC) <http://www.nacac.org/policy/orphanages.html>

Yet the “either-or” approach to the care of vulnerable children (that is, *either* family/community-based care *or* institutional care) is problematic for a number of reasons, which are outlined below.

*History suggests otherwise*

The “either-or” approach to thinking about care for vulnerable children rests on a particular reading of history. Scholars have pointed out that this version of history assumes a linear progression from a past dominated by family-based care to the rise of the welfare state in which informal kinship care is supplanted by statutory institutional care. Moreover, the not implicit point made is that there can be a return to this “golden age” of the family – where relatives re-assume their roles as society’s primary care providers.<sup>23</sup>

Yet, what emerges through careful historical analysis of the supposed “golden age of family” is that a “complicated and shifting ‘mixed economy’ of care, in which the role of the *immediate* family may have been overestimated” can be traced as far back as antiquity. Evidence points to the fact that as well as informal community networks which provided an extra source of support for the otherwise insufficient care that families were able to provide the ill, disabled or poor – “vertical” ties such as those linking patrons and clients, benefactors and the poor” were always crucial. Rather than undermining or replacing family and community ties, it is argued, those vertical ties served, in many ways, to supplement and as a result often strengthen them.<sup>24</sup>

Therefore, to “return” to the past form of care, as some advocates of alternative care seem to be espousing, would be to return to a “mixed-economy of care” – and not, as they suggest, family-based care.

*Many “alternatives” to institutions spearheaded by institutions themselves*

The second reason that the “either-or” approach is problematic is that by presenting family or community-based care as “alternatives” to institutional care, proponents of this view miss the point that historically, long-term institutional care facilities have spearheaded a number of the key healthcare initiatives (particularly to do with community outreach) that are now being presented as “alternatives” to those very institutions. This point was made cogently by Jerome Kaplan as far back as 1974 in his reflections following the conference held by The National Association of Jewish Homes for Aging, where he also listed a number of institutionally-backed “alternative” initiatives:

“... it should be mentioned – among others – that the longest continuous USA Meals on Wheels service with full, individual diets provided to an entire community is institutionally based and institutionally motivated; that independent housing, whether through apartments,

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<sup>23</sup> Horden, Peregrine and Smith, Richard (2007) Introduction to The Locus of Care: Families, Communities, Institutions and the provision of welfare since antiquity. Routledge, 2007

<sup>24</sup> Ibid.

cottages or other modes was institutionally motivated and begun; that major home health aide services were initiated through the institution; that the physical, occupational, and speech therapies to the elderly for outpatient and in-house service was institutionally pushed along with the newer added concept of the importance of such therapies for maintenance; and, the list can grow.”<sup>25</sup>

Kaplan’s point about care for the elderly and the potential effectiveness of institutionally-coordinated community services has strong relevance for the care of CLHA also as will be discussed in relation to SCH in Sections 4 and 5.

### *Dismisses the possibility of a blended model*

The “either-or” assumption dismisses or at the very least underplays any possibility of combining elements of institutional care and the alternatives provided. Yet in the case of elderly care, for example, a number of people have advocated a “coordinated programme of institutional and parallel services – a supermarket of services” in which the institution is considered “one link in the chain of services”<sup>26</sup>

In a similar fashion, the suggestion made in this paper is that SCH, which is intricately connected with Karnataka’s Community Care Centres on multiple levels: from family tracing to information sharing, from outreach services to follow-up care, demonstrates the extent to which it is possible to combine the benefits of both institutional care and community-based alternatives while offsetting a number of the disadvantages of each. A detailed discussion of the specific features and implications of this blended model is provided in Section 5.

### Assumption 2: Family and community-based care as the *universally* best options

The policies put forward by the UN, STC and other organizations advocating alternatives to institutional care for children are universal in their scope. Indeed, commenting on the UN-set international guidelines for alternative care, STC notes that: “[t]he new international Guidelines set out clear quality standards that should be met by all forms of alternative care. They are universal, based on the UN Charter for the Rights of the Child (UNCRC), and apply to all settings regardless of their culture or financial and political status.”<sup>27</sup> Amongst other things, these Guidelines set out to more effectively monitor existing institutions, provide better “gate-keeping”, restrict the use of institutional care especially for those under the age of three and importantly, place all of this within an over-all strategy of deinstitutionalization.

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<sup>25</sup> Kaplan, Jerome (1974). The Institution as the Cornerstone for Alternatives to Institutionalization, *The Gerontologist* [online] Available at: <http://gerontologist.oxfordjournals.org/content/14/1/5.full.pdf>

<sup>26</sup> Shore, Herbert (1974). What’s New About Alternatives? *The Gerontologist* (1974) 14 (1): 6-11 [online] Available at: <http://gerontologist.oxfordjournals.org/content/14/1/6.full.pdf+html>

<sup>27</sup> Save The Children (2009). Keeping Children out of Harmful Institutions: Why we should be investing in family-based care. The Save The Children Fund (2009) [online] Available at: [http://www.savethechildren.org.uk/sites/default/files/docs/Keeping\\_Children\\_Out\\_of\\_Harmful\\_Institutions\\_Final\\_20.11.09\\_1.pdf](http://www.savethechildren.org.uk/sites/default/files/docs/Keeping_Children_Out_of_Harmful_Institutions_Final_20.11.09_1.pdf)



Yet their well-meaning efforts to safeguard the welfare of all children equally are difficult to apply in countries where factors militate against the proposed “alternatives.”

### *Adoption and Foster Care in India*

Even the staunchest advocates of family-based care appreciate that this is not always possible – either because the child has been orphaned or because some biological parents - for medical or other reasons - are unable to care for their child. This is particularly true for CLHA, who are likely to have lost their parents to AIDS or have parent(s) with seriously compromised health – parent(s) who may not have long to live. For this reason, foster care or adoption are typically presented as viable alternatives to institutional care for these children to be able to be brought up in an environment which is as home-like as possible.

In these documents, the alternatives of foster care and adoption are presented as universal. This ignores the fact that a number of cultural and historical factors militate against these options in some countries. Most relevant to the present study, the striking absence of foster care across India has been noted.<sup>28</sup>

In their international comparative study of foster care, George and Oudenhoven cite research which found that one pilot foster scheme in India placed just twenty-four children with twenty families in ten years, while the large metropolis of Delhi had only four hundred and fifty children in formal foster care. The authors point out that this research was quoting figures from the seventies and eighties, and make the pertinent observation that the “absence of current and detailed figures also illustrates the relative insignificance of formal fostering in India”<sup>29</sup>. Various reasons for why foster care has proven difficult to implement in India have been cited – but they include the difficulties of identifying foster carers with “appropriate motivation and adequate housing” and “problems of ‘matching’ children and foster carers around issues of caste, religion, colour and language.”<sup>30</sup> Interestingly, work on child care in Cape Town, has also pointed to the dearth of formal foster care or adoption amongst the Indian community compared to the African community during the apartheid era<sup>31</sup> - suggesting that this resistance to foster care may not be transient.

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<sup>28</sup> See report produced by Ministry of Women and Child Development, Government of India and supported by UNICEF and STC, which states that: “India continues to use institutionalization as a method of providing services to children in difficult circumstances. Although internationally it is now an established fact that institutionalization is not in the best interest of the child, yet, in countries like India, where the number of children in need of care and protection is very high and the non-institutional methods of care are not developed, the institutionalization of children will continue till alternatives are identified” ‘Study on Child Abuse: India 2007’ [online] Available at: <http://wcd.nic.in/childabuse.pdf>. (quote from p. 125)

<sup>29</sup> George, Shanti and van Oudenhoven, Nico (2002), quoting research by Singh (1997:124 and 128). *Stakeholders in Foster Care: An International Comparative Study*. IFCO & Garant Publishers (2002), p. 54

<sup>30</sup> Tolfree, D. (1995). *Roofs and Roots: The Care of Separated Children in the Developing World*. Save the Children Fund, UK (1995), pp. 275-6 [online] Available at: <http://www.crin.org/docs/roofs%20and%20roots.%20%20the%20care%20of%20separated%20children%20in%20the%20deve.pdf>

<sup>31</sup> Burman, Sandra and van der Spuy, Patricia, ‘Communities, ‘Caring’, and Institutions: Apartheid and child care in Cape Town since 1948’ (Chapter 10) in Horden, Peregrine and Smith, Richard (2007) *The Locus of Care: Families, Communities, Institutions and the provision of welfare since antiquity*. Routledge, 2007, pp. 239-258

With the stigma surrounding HIV/ AIDS being so strong that many infected children are actually (unofficially) prevented from attending school in their communities owing to the fear of fellow students' parents, the prospect of being fostered or adopted is an even more distant one for Indian CLHA. Indeed, the discriminatory outcomes of adoption and foster care services – from places like Cape Town where long lists of white couples are queuing to adopt while black African children end up on the streets<sup>32</sup> – to the USA, where research shows how a number of minority communities have been seriously short-changed by the foster care system,<sup>33</sup> demonstrate the dangers of assuming that those deinstitutionalized will be readily absorbed by these “alternatives.”

### *The problem with Kinship care*

When care by the nuclear family is not possible, kinship-based care – or care by the extended family – has traditionally been the more frequent practice in India. The reasons are multiple, but they include the traditional importance of the extended family in Indian culture and are arguably not unrelated to the collective memory of non-kinship fostering as a colonialist socialization of tribal Indian children into mainstream American culture between the mid-19<sup>th</sup> and mid-20<sup>th</sup> centuries.<sup>34</sup>

Kinship-based care has been proposed as an alternative to institutional care for orphaned children or children whose parents are unable to care for them. Indeed, because it involves blood ties and therefore, it is assumed, is based on a sense of familial loyalty and genuine affection, it is often presented as the preferred alternative over formal, non-kinship-based foster care or adoption.<sup>35</sup>

Yet this assumption can lead to a number of dangers. Evidence has been cited that it leads to less monitoring than formal fostering, for example.<sup>36</sup> At SCH, one staff member recounted the case of one girl, formerly under the institution's care, who was sold into sex slavery by her uncle. By appealing to our sense of family as a safe haven, kinship care appears innocuous, but, as this girl's experience demonstrates, that is clearly not always the case.

In many ways, this would be an argument in favour of better monitoring of kinship care, rather than the continued need for institutional care.

Yet other serious challenges surrounding kinship care remain – the solutions for which are far less straightforward. As has been the case elsewhere, mammoth changes have been occurring

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<sup>32</sup> Ibid.

<sup>33</sup> See, for example, Barbell, Kathy and Freundlich, Madelyn (2001) *Foster Care Today*. Casey Family Programs, Washington DC (2001) p. 5 [online] Available at: [http://www.hunter.cuny.edu/socwork/nrcfcpp/downloads/policy-issues/foster\\_care\\_today.pdf](http://www.hunter.cuny.edu/socwork/nrcfcpp/downloads/policy-issues/foster_care_today.pdf)

<sup>34</sup> Indeed the Indian Child Welfare Act (ICWA) was largely developed as a response to this – a way of checking the practice of forcefully removing children from tribal families. See <http://library.adoption.com/articles/the-indian-child-welfare-act-.html>

<sup>35</sup> Schuerman, John R., Rzepnicki, Tina L and Littell, Julia (1994). *Putting Families First: An Experiment in Family Preservation*. Walter de Gruyter, Inc. New York (1994)

<sup>36</sup> Ibid. and Geen, R. (n.d.) *The Evolution of Kinship Care Policy and Practice*. Children, Families and Foster Care [online] Available at: [http://www.princeton.edu/futureofchildren/publications/docs/14\\_01\\_07.pdf](http://www.princeton.edu/futureofchildren/publications/docs/14_01_07.pdf)

in India as it navigates through the twists and turns of its developmental trajectory. One striking feature of this has been the breaking up of extended families through urbanization – the most recent census confirming the shift to an increasingly nuclear family living arrangement.<sup>37</sup> Moreover, as urbanization proceeds unevenly, and development creates new pressures, chronic poverty remains a real and in some senses a growing problem for a sizeable portion of the Indian population. Indeed, according to the most recent government estimates 354, 600, 000 people are living below the (contentiously defined) poverty line in India today.<sup>38</sup>

In his study on Foster Care in the US, Rob Geen notes that “Kinship foster parents tend to be older and have lower incomes, poorer health, and less education than non-kin foster parents.”<sup>39</sup> These findings have been replicated elsewhere.<sup>40</sup> As extended families are broken up, and as financial pressures make it difficult for people to sustain even their own nuclear families, one must question the extent to which even the most well-meaning extended kin can cope with the burden of taking in a niece, nephew or grandchild with multiple needs such as CLHA that may require even more financial and emotional investment than a healthy child.<sup>41</sup>

Indeed, it is clear from both staff interviews as well as statistics (see Appendix 1), that a number of aunts and uncles of children at SCH find it challenging even to manage regular visits – many of them involved in agricultural work and dependent on a daily wage. For these children, kinship care would mean living in a mostly empty house, until aunts and uncles return home from a hard day’s work. The current government scheme, which gives 700 rupees a month to those caring for CLHA in their homes, can hardly be seen as an effective solution – since in the overwhelming majority of cases, the children’s extended kin are struggling even as the financial burden of caring for the ill child is carried completely by SCH.

Aside from aunts and uncles, grandparents frequently assume the care of CLHA when the latter lose their biological parents or when these are unable to care for them. Comparative studies amongst ethnic groups within the US show that non-white children without biological

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<sup>37</sup> The Hindu (14/03/12) [Census Sheds new light on changing India](#)

<sup>38</sup> Balchand, K. (20/03/12). Now, Planning Commission lowers the poverty line. The Hindu [online] Available at: <http://www.thehindu.com/news/national/article3013870.ece>

<sup>39</sup> Geen, R. (n.d.) The Evolution of Kinship Care Policy and Practice. Children, Families and Foster Care [online] Available at: [http://www.princeton.edu/futureofchildren/publications/docs/14\\_01\\_07.pdf](http://www.princeton.edu/futureofchildren/publications/docs/14_01_07.pdf)

<sup>40</sup> Harden et al., 1997 cited in Grant, R. (2000). The Special Needs of Children in Kinship Care in Grandparents as Carers of Children with Disabilities: Facing the Challenges. Edited by McCallion, P. And Janicki, M. The Haworth Press, Inc. (2000)

<sup>41</sup> In their research on child care in post-Apartheid Cape Town, Burman and van der Spuy note that amongst the non-white community, the historical legacy of apartheid, chronic poverty, the breaking up of extended families as a result of racial segregation and urbanization have meant that even the informal, mostly kinship-based fostering that previously took place amongst these communities is today far less likely than it once was. Burman, Sandra and van der Spuy, Patricia, ‘Communities, ‘Caring’, and Institutions: Apartheid and child care in Cape Town since 1948’ (Chapter 10) in Horden, Peregrine and Smith, Richard (2007) [The Locus of Care: Families, Communities, Institutions and the provision of welfare since antiquity](#). Routledge, 2007, pp. 239-258

parents are far more likely to be cared for by a grandparent than are their white counterparts<sup>42</sup> – suggesting that the issue of grandparent caregivers may be of particular relevance in cultures such as India’s where the role of the extended family remains relatively strong and grandparents maintain a significant presence in the lives of their grandchildren. At SCH, eight of the one hundred children have a grandparent as their primary caregiver (see Appendix 2).

Yet a number of findings raise serious concerns about grandparent care for vulnerable children. In ‘From Roots to Roots’, Tolfree reports research in Uganda which “found that behavioural problems were common in grandparent-headed households.” The study found that children who had a grandparent in their fifties and sixties as a caretaker were “vulnerable to malnutrition and infectious diseases because food production was low and medical care could not be afforded.” Unsurprisingly, the book’s author cites a 1992 study by Barnett and Blaikie which found that problems were exacerbated when the grandparent was single and female. The author also makes the pertinent point that vulnerable children being cared for by a grandparent will “experience further trauma” when their elderly caregivers pass away.<sup>43</sup>

A US-based study “found that custodial grandparents have a 50% higher chance of having a daily activity limitation. They report lower satisfaction with their own health and rate their health status lower than do non-custodial grandparents.”<sup>44</sup>

SCH runs an outreach programme in Kolar in collaboration with ‘Sisters of Precious Blood’ – a faith-based Community Care Centre (see Section 5). One nurse working in the outreach programme explained to this author that ART adherence is often more challenging when it comes to CLHA living in grandparent-headed households. The tendency for grandparents to forget, or to insist on giving children herbal medicines which interfere with the ART medication is a serious concern which she says she and the other staff member at ‘Sisters of Precious Blood’ often find themselves battling with.

The significant challenges surrounding formal foster care as well as kinship care for CLHA call for caution in espousing these alternatives as universally preferable to institutionalization.

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<sup>42</sup> Fuller-Thomson, Minkler and Driver, 1997 cited by Grant, R. (2000). ‘The Special Needs of Children in Kinship Care’ in Grandparents as Carers of Children with Disabilities: Facing the Challenges. Edited by McCallion, P. And Janicki, M. The Haworth Press, Inc. (2000), p. 18

<sup>43</sup> Tolfree, D. (1995). *Roofs and Roots: The Care of Separated Children in the Developing World*. Save the Children Fund, UK (1995), p. 33 [online] Available at: <http://www.crin.org/docs/roofs%20and%20roots.%20%20the%20care%20of%20separated%20children%20in%20the%20deve.pdf>

<sup>44</sup> Minkler & Fuller-Thomson (1999) cited in Grant, R. (2000). ‘The Special Needs of Children in Kinship Care’ in Grandparents as Carers of Children with Disabilities: Facing the Challenges. Edited by McCallion, P. And Janicki, M. The Haworth Press, Inc. (2000), p. 20

### Assumption 3: Community-based care and institutional care cater for the same populations

Whilst it is generally recognised that institutional care will be necessary for a subsection of the vulnerable child population, a clear implication of the “alternatives” discourse is that these alternatives can, for the most part, replace institutional services. The implication being that in the majority of cases, the beneficiaries of institutional care and family or community care are the same.

The limitations of this view in the cases of adoption and fostering were highlighted above.

Beyond fostering and adoption, much talk of alternative care for the institutionalized emphasizes the need to extend and strengthen social support mechanisms. Community-based organisations and social welfare agencies are seen as being able to provide support to the families (biological or otherwise) of vulnerable children while keeping the latter out of institutions.

There is little doubt that strengthening community-based social services is a positive step toward catering for the multiple needs of the disadvantaged, in this case CLHA and their families. Yet here too, assuming that the “alternative” of community care targets the same populations that would otherwise have resided in institutions is problematic.

#### *Social service “creaming”*

The problem of “creaming” in social services remains a glaring one. As Schuerman has noted, “many programs appear to... favour the acceptance of “better” or “easier” cases, cases that are relatively less needy.” Amongst other examples, he points to community mental health centres, a large number of which were originally established to cater for the chronically ill discharged from large state psychiatric hospitals but who “now devote most of their resources to treatment of less severely ill patients.” Other examples he mentions include “family support centres, job training programmes, and many Head Start centers.”<sup>45</sup>

In the case of India, a look at how Targeted Intervention programs (TIs) for PLHA have fared is instructive. TIs have been one of the main mechanisms for reducing transmission of HIV across India under the National AIDS Control Programme (NACP-II). Statistics indicate that 2008 saw a significant decline in transmission rates amongst female sex workers in high HIV prevalence southern districts as compared to 2001 in places where TIs were intense.<sup>46</sup> Yet a 2007 parliamentary committee report reveals that this is only part of the picture. As of 2007, 45% of sex workers, 47% of injecting drug users and a staggering 94% of men who have sex with men – all considered “target” vulnerable populations – had not received any intervention. Moreover, the committee noted that the Department of Health presented no figures for the Male Sex Worker population, suggesting that they either “do not have the

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<sup>45</sup> Schuerman, John R., Rzepnicki, Tina L and Littell, Julia (1994). *Putting Families First: An Experiment in Family Preservation*. Walter de Gruyter, Inc. New York (1994)

<sup>46</sup> Kumar, Rajesh et al. (2011). Impact of targeted interventions on heterosexual transmission of HIV in India. *BMC Public Health*; 2011, 11:549 [Online] Available at: <http://www.biomedcentral.com/1471-2458/11/549>

figures of estimated coverage or they are simply not covered at all.”<sup>47</sup> The idea that the acutely vulnerable can be equally and even better served by targeted social policies is challenged by these findings.

Even if social policies are considerably improved, a number of vulnerable people – often the most vulnerable – are always liable to fall off their radar. For many of these people and their children, the institution is often the only point of call.

### *Weakened public voice*

There is another sense in which deinstitutionalization can lead to “creaming.” As it stands, a number of pioneering institutions, such as Snehadan, which is now considered a learning site for caregivers of PLHA across the country, occupy more than just a caregiver role. With an acute, in-depth understanding of the multiple needs of those under their care, they also become a crucial voice in the public arena: raising important issues and informing policy based on practical experience. One of the serious consequences of dismantling these kinds of pioneering institutions is the resulting fragmentation of vulnerable populations from a public voice point of view.

Even if their immediate medical needs are met by community-based social services, it is doubtful whether an acutely vulnerable population – such as the adults and in this case children, living with HIV/ AIDS - can raise their voices in a similarly coordinated and effective manner. It has often been commented that one of the injustices of a democratic society is that even as it purports to provide everyone with a voice, it is repeatedly those most capable of organizing themselves effectively that are heard. The cruel irony being that those encountering serious barriers to that kind of organization (economic, educational, health-related etc) – are likely to be those whose needs are most urgent.

To sum up, the argument is not to abandon the idea of better, more efficient and effective community-based social welfare, certainly that is to be encouraged. Nor is it to lambast social services for “creaming” the less severe cases – though experiments in improving the targeting of services are of course to be welcomed. Rather it is to highlight some of the deficiencies of community care, of social welfare as a universally better “alternative” to institutional care as it is presented in the “either-or” model. Experience has shown that in a number of cases, the two cater for different types of populations – with those in institutional care typically exhibiting a plethora of problems that make their stay in a facility which can address those multiple needs the best option for them. The fact that community-based care and care in an institutional setting tend to target different populations makes the promotion of one over the other deeply problematic.

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<sup>47</sup> Parliament of India, Rajya Sabha (2007). Department-related Parliamentary Standing Committee on Health and Family Welfare, Twenty-second Report on Demands for Grants 2007-2008 (Demand no. 46) of the Department of Health and Family Welfare (Ministry of Health and Family Welfare) (laid on the table of Lok Sabha on 3<sup>rd</sup> May, 2007) [online] Available at: <http://164.100.47.5/book2/reports/health/22ndreport.htm#composition>

Assumption 4: “Family (re)integration” and “community (re)integration” are unproblematic concepts

An overwhelmingly common feature of the policy documents outlined in this paper is their unqualified use of the concepts of “family (re)integration” and “community (re)integration” in a way which suggests their meaning is both straightforward and unproblematic.

This is an important point since in almost all cases the stated goal of the “alternatives” agenda is that of “family reintegration” for the institutionalized whose biological families are alive or “family integration” for those put up for adoption, or who are entered into foster or kinship care. Community integration or re-integration is seen as flowing automatically once children are transferred from an institution to a family setting.

What is overlooked is that one of the goals of future-oriented institutional care is in fact to lay the foundations for the child to eventually decide *which* community he or she wishes to integrate into. We live in an age in which we increasingly talk of “migrants of identity”<sup>48</sup> – where people regularly relocate for work reasons, start their own families and negotiate new, no less strong links with parents and relatives back home even as they “integrate” into their new communities. SCH’s director Fr Mathew says there is a kind of double-standard at work in the well-meaning efforts to “reintegrate” children in care. “Why do we tell these children: you can’t do that? Why does integration for the child in the care system necessarily mean returning to his or her village and working for a daily wage on some else’s farm? Why can’t it also mean finding a job in the service sector in Bangalore?”

The documents appear to present the goals of family integration and successful community integration as synonymous. This is despite the worrying findings that a sizeable number of children who are placed in foster care “age out” in the system and enter society woefully ill-equipped for successful “community integration.”<sup>49</sup> Indeed one US-based longitudinal study carried out in the early nineties found 49% of the young people discharged from foster care were employed, compared to a national employment level for 16 to 24 year olds of 65%. A later study of a cohort of youth who had been out of care for 12 to 18 months found that 37% and 32% had not finished high school and were receiving public assistance respectively.<sup>50</sup>

It can be countered that there will always be cases of children being brought up in ways that do not prepare them for successful adult life. Those making this argument might say that all that the state can do is provide the child with the best possible chances for its future, and that for all its faults it is still family care or family-like care rather than institutional care that provides the best possible chances. Yet while that may be true in a large number of cases, it is difficult to make such categorical statements when it comes to children facing the myriad

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<sup>48</sup> Rapport, Nigel and Dawson, Andrew (1998). Migrants of Identity: perceptions of home in a world of movement. Berg (1998). The authors describe “movement” as “the quintessential experiences of our age.”

<sup>49</sup> Barbell, Kathy and Freundlich, Madelyn (2001) Foster Care Today. Casey Family Programs, Washington DC (2001) p. 5 [online] Available at: [http://www.hunter.cuny.edu/socwork/nrcfcpp/downloads/policy-issues/foster\\_care\\_today.pdf](http://www.hunter.cuny.edu/socwork/nrcfcpp/downloads/policy-issues/foster_care_today.pdf)

<sup>50</sup> Longitudinal study on employment by Westat (1991) and study on high school completion and public assistance by Courtney and Piliavin (1998). Both studies cited in *ibid*.

physical health, psychosocial and frequently socioeconomic challenges that come with HIV – challenges that require a highly specialized, multifaceted approach that even field experts are still grappling with.

The point is not to argue that institutional care prepares children for independent living while the proposed “alternatives” do not. Instead it is to say that the rigid goal of “family integration at all costs” does not *ensure* successful community integration and may *in some cases* positively discourage it. That is if “community integration” is understood to be an independent adult with the skills to build a life for him or herself wherever he or she chooses to - rather than simply being physically part of a community. Fr Mathew points out that this apparent disjuncture between child and youth policy is particularly worrying in light of recent reports on the unemployability of the vast majority of Indian youth.<sup>51</sup> “This is the India that these children – who are facing far more challenges than the average Indian youngster - are going into.”

### *The Future is Now*

As Eva Kittay puts it in her *Boston Review* article, “the problem with having children is that once you have them, you have them.”<sup>52</sup> The issue of the future-orientation of current child policy cuts to the heart of the discussion surrounding alternative care. Whilst it has rightly been argued that child policy which sees the child as an ‘adult in waiting’ more than a ‘child in the here and now’ creates its own problems,<sup>53</sup> few would deny the serious costs - to both children and society – of creating short-sighted child policies – particularly for vulnerable children.

At SCH, plans are currently underway to provide a “second phase” to the services it provides – where children who reach the age of 13 move to for vocational training. In the “first phase” (SCH as it is today), SCH staff members are given specific instructions to focus on identifying the particular skills and talents of the children under their care. The idea is to use the second phase as an opportunity to hone those skills. As a result, it is arguable that the model that SCH is working toward is also “blended” in the sense that it is working towards blending child and youth education and training.

Fr Mathew argues that when it comes to children with a chronic illness such as HIV/ AIDS who face an uncertain future, and whose parents may not have long to live, future-oriented policies are particularly crucial. In an individual interview for the present study, he described his long-term vision of establishing a mentorship programme, where individual donors who sponsor children’s material care while at SCH become a source of emotional, social and professional support throughout the child’s stay in the institutional setting as well as

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<sup>51</sup> See for example Deccan Herald (cd) Huge number of Indian youth remain unemployable, says report [online] Available at: <http://www.deccanherald.com/content/123832/content/214731/content/219231/jpl-2012.html>

<sup>52</sup> Kittay, E. (2004). Falling Short. *Boston Review* [online] Available at: <http://bostonreview.net/BR29.2/kittay.html>

<sup>53</sup> See for example Lewis, J. (2006). *Children, Families and Welfare States*. Edward Elgar Publishing Ltd. Lewis argues that the UK and Canadian models of child policy have elements of this ‘adult in waiting’ rather than ‘children in the here and now’ approach.



following discharge. The other goal is of an alumni network of past SCH beneficiaries who, once discharged, may find it helpful to reach out to one another for various forms of support – much like university graduates entering a new phase of their lives.

SCH's "sibling programme", which was being discussed and planned at the time of this paper's writing, is also considered key to this future-oriented approach. Fr Mathew maintains that linking the children at SCH to negative elder siblings – who are highly likely to outlive their parents – is one crucial way of ensuring some kind of long-term support for these children once they are discharged. The fledgling sibling programme is discussed in more detail in chapter 4.

In sum, the multiple challenges faced by CLHA and their families call for more critical reflection about concepts like family integration, community integration and independent living than is offered in a number of the documents calling for deinstitutionalization. While practical considerations preclude a comprehensive approach to these issues in the present paper, the analysis of SCH-family-community ties within the blended model will, it is hoped, provide a catalyst for such critical reflection.

## Private Boarding Schools versus Institutional Care

### Two separate languages?

*“When residential forms of care are criticised, reference is more likely to be made to approved schools and mental hospitals than to Eton, or to Kings College Cambridge!”*

David Tolfree, Save the Children Fund, UK<sup>54</sup>

A number of people have drawn attention to the striking difference in the way that we approach long-term residency in boarding schools as opposed to long-term care in institutional settings. In her memoir tellingly titled “Orphans: Real and Imaginary”, Eileen Simpson looks back on her experience at a convent boarding school ‘The Villa’ and writes of her gratefulness that the veneer of prestige and social acceptability was kept even though the school she attended was essentially an orphanage. “An orphan who goes to an orphanage is far more orphaned than one who goes to a convent boarding school,” she says.<sup>55</sup>

One – and arguably the only - contention in defence of this apparent double standard is that conditions in boarding schools are better than those in institutional care - that the harm and neglect that is potentially experienced by children within institutional care does not extend to boarders. Yet evidence supporting this contention is conspicuous by its absence.

Indeed, their public acceptability means that for the most part, boarding schools continue to operate outside of policymakers’, social workers’ and monitoring agencies’ gaze. In the case of the UK, for example, journalist George Monbiot, himself a former boarder, points out that the National Society for the Prevention of Cruelty to Children (NSPCC) “has never compiled a report on private boarding schools, has no data and no information.” And this despite the growing trend for British parents to send their children away to boarding schools.<sup>56</sup>

Psychotherapist and founder of the group “Boarding School Survivors” Nick Duffell has been giving group workshops to male ex-boarders for over sixteen years. Having attended a private boarding school for ten years as a child, and – interestingly – taught in an Indian boarding school for two, his 2005 article makes the pertinent observation that only one serious sociological study of boarding schools had been conducted until that date – Lambert’s. And

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<sup>54</sup> Tolfree, D. (1995). *Roofs and Roots: The Care of Separated Children in the Developing World*. Save the Children Fund, UK (1995), p. 81 [online] Available at: <http://www.crin.org/docs/roofs%20and%20roots.%20%20the%20care%20of%20separated%20children%20in%20the%20deve.pdf>

<sup>55</sup> Eileen Simpson citation is from Weisman, M. (1994) ‘When Parents are not in the best interests of the child’ [The Atlantic Online] Available at: <http://www.theatlantic.com/past/docs/issues/96apr/orphan/weisorp.htm>

<sup>56</sup> In the 12 months between November 2010 and 2011, figures showed an increase in the number of children boarding until the age of 13 increased by more than 5 percent and “schools are now building new boarding facilities to cope with demand” says Moyes, J. (11/11) Boarding schools – one way to beat the nanny fees. The Telegraph [online] Available at: <http://www.telegraph.co.uk/education/8874599/Boarding-schools-one-way-to-beat-the-nanny-fees.html>

that dated back to the 1960s.<sup>57</sup> While this author did find some academic material on the potential psychological damage caused by attending boarding school,<sup>58</sup> from both a scholarly perspective as well as a practical policy angle, the attempt to look into the quality and effects of private boarding is nowhere near that made in relation to institutional care.

Since there is little sound evidence to back up the claim that the boarding school system for the privileged is automatically and innately less harmful than institutional care for vulnerable children, perhaps the emphasis should be on the quality of care and education being provided to children in each - rather than on where it is provided.

It is this firm belief that the “anti-institutional” mantra should not become an ideologically entrenched position that guides the approach in the next section. While the focus is on one particular institution for CLHA: Sneha Care Home, the aim of the case study is also to provide a catalyst for thinking more creatively and less monolithically about institutional care in general and the relationship between institutional care and family/ community-based alternatives in particular.

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<sup>57</sup> Duffell, N. (2005). Surviving the Privilege of Boarding School. Draft article for Mental Health Assn, Qld, Australia [online] Available at: <http://www.boardingrecovery.com/images/SurvivingthePrivilege.pdf>

<sup>58</sup> See for example Shaverien, J. (2004). Boarding school: the trauma of the ‘privileged’ child. *Journal of Analytical Psychology*, Vol. 49 (5): 683-795

## PART II

### 4

#### The Institution as Site for Family Integration

Contrary to common perceptions of institutional care settings as refuges for the parentless, (admittedly patchy) available evidence indicates that globally, at least four out of every five of the eight million children living in long-term institutional care have one or both parents alive.<sup>59</sup>

##### *Impact of institutional care on family relationships: a literature review*

While it might be assumed that institutional placement would sever or weaken familial relations, evidence points to the positive effects that placing a family member in institutional care can have in terms of improving family ties and dynamics. In the case of the elderly, for example, it has been found that “nursing home placement leads to renewed or discovered closeness of familial bonds”<sup>60</sup> – a fact that may be at least partially attributable to the sense of “relief” that family members feel at having some of the enormous strain of direct care lifted off their shoulders.<sup>61</sup> One study looking at structured family leisure programmes in the context of Alzheimer’s patients in institutional care noted the “alleviating” effect this had on the “caregiver burden” of family members.<sup>62</sup> Demonstrating institutional care’s potential long-term benefits for family dynamics was a longitudinal study which interviewed the families of children with mental retardation who had received residential treatment both one and two years after placement. The study found that “respondents primarily reported post-placement benefits to the family.” Crucially, however, the study also noted that in this particular case, family involvement in the children’s treatment programme while they were institutionalized was “high and stable.” This suggests that the level of family members’ involvement in the care of the institutionalized may determine the extent to which institutional care can bolster familial ties during care and post-discharge. Indeed, a renowned longitudinal study carried out in the 1960s – “The Cleveland Bellefaire follow-up study” – found that for children leaving institutions and returning to their families and communities,

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<sup>59</sup> Save The Children (2009). Keeping Children out of Harmful Institutions: Why we should be investing in family-based care. The Save the Children Fund (2009) [online] Available at: [http://www.savethechildren.org.uk/sites/default/files/docs/Keeping\\_Children\\_Out\\_of\\_Harmful\\_Institutions\\_Final\\_20.11.09\\_1.pdf](http://www.savethechildren.org.uk/sites/default/files/docs/Keeping_Children_Out_of_Harmful_Institutions_Final_20.11.09_1.pdf), p. STC notes that there are likely to be far more than eight million children currently in institutional care.

<sup>60</sup> Smith and Bengston (1979) cited by Bowers, BJ. (1988). Family Perceptions of Care in a Nursing Home. *The Gerontologist* (1988) 28 (3): 361-368 [online] Available at: <http://gerontologist.oxfordjournals.org/content/28/3/361.full.pdf>

<sup>61</sup> Donahue, 1969; Smith and Bengston, 1979) cited by Montgomery, Rhonda J.V. (1982). Impact of Institutional Care Policies on Family Integration. *The Gerontologist* (1982) 22 (1): 54-58, p. 3 [online] Available at: <http://gerontologist.oxfordjournals.org/content/22/1/54.full.pdf+html>

<sup>62</sup> Depuis, S.L.; Pedlar, A. (1995) Family leisure programs in institutional care settings: buffering the stress of caregivers. *Therapeutic Recreation Journal* 1995 Vol. 29 No. 3 pp. 184-205 [online] Available at: <http://www.cabdirect.org/abstracts/19961802055.html;jsessionid=B21446DBB01586ED3D3112DEDFC0F31F>

the gains accrued from institutional care tended to last longer if staff worked with parents and community agents for a transitional period once the child was discharged.<sup>63</sup>

Notwithstanding the demonstrated benefits of family involvement in children's long-term institutional care, "(l)ack of planned and nurtured contact between children in residential care and their families was found to be an almost universal phenomenon in the countries covered by Save the Children's research. It is extremely rare to find any institution which positively values family contact."<sup>64</sup>

In light of this point, the next section explores and analyses the extent and type of family involvement in the long-term care of children at one particular institution: SCH.

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<sup>63</sup> Cited in Weisman, M. (1994) 'When Parents are not in the best interests of the child' [The Atlantic Online] Available at: <http://www.theatlantic.com/past/docs/issues/96apr/orphan/weisorp.htm> (Accessed 29/04/12)

<sup>64</sup> Tolfree, D. (1995). *Roofs and Roots: The Care of Separated Children in the Developing World*. Save the Children Fund, UK (1995), p. 78 [online] Available at: <http://www.crin.org/docs/roofs%20and%20roots.%20%20the%20care%20of%20separated%20children%20in%20the%20deve.pdf>

The role of the primary caregiver in CLHA's long-term institutional care: The case of SCH

“We always say: this is not an orphanage.”

(Fr Mathew Perumpil, SCH Director)

“We try our best but we have our limitations no? We [SCH staff and Primary Caregivers] need each other.”

(Counsellor, SCH Social Care Department)

While priority for admission is given to HIV positive orphans, over half of the children currently at SCH have one or both parents alive (see Table 1). A number of factors - not least the continued improvement in quality of, and access to, Anti-Retroviral Therapy (ART)<sup>65</sup> for parents living with HIV/ AIDS - make orphanhood less of an inevitability for their children than it once was.

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<sup>65</sup> While until recently HIV/ AIDS was considered a killer disease – it is now seen as a manageable chronic illness - in part thanks to wider access and use of ART medication which fights the HIV virus for a 12-hour period. The Indian central government made ART medication freely available in the year 2000. Within three years of the policy's introduction, ART centres were introduced in almost every district across India – so there is now a centre within a 30 to 40 km distance of everyone. For those with a low CD-4 count, ART medication taken twice daily, at the same time, coupled with good nutrition and medical care, enables many HIV patients to lead a relatively normal and active life, even while it presents its own complications.

Table 1: Parental status of children at SCH

<b>TOTAL NO. OF CHILDREN</b>	<b>100</b>
No. of Boys	55
No. of Girls	45
Siblings	17
<b>PARENTAL STATUS</b>	
<i>Orphans</i>	40
Boys	21
Girls	19
<i>Single parents</i>	52
Boys	30
Girls	22
Maternal Orphans	10
Paternal orphans	42
<i>Both alive</i>	08

(Sneha Care Home Statistics 2011-2012)

It should be noted at the outset that “primary caregiver” is the technical term used by SCH to refer to the person – outside of SCH staff - who is primarily responsible for any major decisions regarding the child. The primary caregiver is responsible for decisions like the child’s enrolment in SCH (subject to SCH acceptance) and discharge. The primary caregiver is also responsible for phoning and visiting the child and taking the child home for holiday(s). If alive, parents automatically assume this status. In cases where the child is an orphan this role is typically assumed by a willing extended kin. In the rare cases where neither care by a parent nor by an extended kin is possible, another individual will take up this role based on their willingness, suitability and, crucially, consultation with the child. It should be noted that until recently there was only one child at SCH whose primary caregiver was a non-family member – and since that primary caregiver was found wanting – SCH staff are now working to trace a relative of the child to serve as an alternative primary caregiver for her (see Appendix 2).

Unless the point calls for specification as to whether a parent, extended kin or an non-relative entrusted with the child’s care is being referred to, the “PCG” (primary caregiver) will be used, and should be taken to mean any of these three.

### *Who brought them here?*

All the one hundred children currently at SCH were brought to the institution's attention by Community Care Centres (CCCs), NGOs, PLHIV Networks (hereafter jointly referred to as NGOs) or by primary caregivers themselves.<sup>66</sup> As both SCH and NGOs have no legal authority over the children's parents or family members, if the child is accepted into SCH, his or her admission into SCH depends, in the final instance, completely on the primary caregiver's consent. There are currently no cases of child social services having forcefully removed children from their families and placing them in SCH. In settings where such cases arise, this of course complicates things further and raises issues that will not be dealt with in this paper. Moreover, all the children are between the ages of four and ten<sup>67</sup> – so the debate about whether those aged three or under are differently affected by care within an institutional setting – as it has been argued - will not be entered into.

### *Why are they here?*

The overwhelming majority of children at SCH – who are all sero-positive<sup>68</sup> - are here for economic reasons and in order to receive an education since one of the key services provided at SCH is schooling for the children under its care at “Shining Star School” (SSS) – which is integrated into the SCH building. That socioeconomic factors and the desire to provide their children with an education are primary motivations for the child's enrolment in SCH is indicated by PCGs' own written accounts in a number of information gathering exercises carried out by SCH as well as SCH staff members in individual interviews.

Table 2 lists the average monthly wages of children's primary caregivers. Of the one hundred PCGs, nineteen did not specify their income on the child's application form, one listed himself as unemployed and another earned both a monthly income of 400 rupees as well as a daily wage of an unspecified amount. Eight of the children's PCGs are daily wage earners earning an average income of just under 54 rupees. Of the remaining seventy one respondents, 65% earned an average monthly income of 2000 rupees or less. Director Fr Mathew points out that looking at PCG income can be misleading. Knowing how much a PCG earns does not tell us how much she or he is prepared to spend on the CLHA. This, he says, is particularly true if an aunt or uncle with children of his or her own is a PCG.

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<sup>66</sup> According to SCH's process documentation manual “The Social Care Department of SCH drafts a primary assessment form to different Community Care Centres (CCCs)/ NGOs in districts of Karnataka... The CCC or the networker carries out primary level assessment in the grass root level.... The filled up primary assessment forms are sent to Sneha are Home through mails or emails. The candidates will be shortlisted, [then] the families are informed” (Sneha Care Home & Shining Star School Process Documentation)

<sup>67</sup> Falling within this age group is one of the criteria for admission (Ibid.). Fr Mathew says that children aged 4 are taken in when they have no other option as in general admission is for children aged five or six – since this is “the natural age for a child to join school.” The upper limit of 10 was introduced to promote – as far as possible – a similar age cohort. “We wanted to avoid an imbalance in the dynamic between children,” says Fr Mathew.

<sup>68</sup> Being Sero-positive is one of the criteria for admission (Ibid.)



In cases where a parent is the PCG, the significant strain that caring for a CLHA involves is often coupled with the PCG's own deteriorating health (see Appendix 3).

Caring for CLHA is made more complicated still since in a number of places across India, enrolment in a community-based school is difficult for CLHA due to stigma. Misinformation fuels fears among fellow students' parents that studying with a CLHA will put their own child at risk, often providing an effective barrier to education for this population.<sup>69</sup>

That socioeconomic deprivation as well as the inaccessibility of education should drive children into institutional care has been noted elsewhere.<sup>70</sup> What is interesting, however, is that many of the children now at SCH had been attending school at the time of their application to SCH. While this would require further exploration, one might hypothesize that the desire to provide a child with education is not necessarily - and perhaps rarely - a sole determinant of institutionalization, but is likely to be one strand of a much wider socioeconomic complex. Fr Mathew says that SCH's decision to adopt the National Institute of Open Schooling (NIOS) curriculum may also go some way toward explaining why family members opt for SCH. The NIOS gives CLHA more flexibility than the standard curriculum and offers a more varied set of options including vocational and "life enrichment" courses which may or may not be subject to formal examination.<sup>71</sup>

Given that "HIV has been described as the fastest way for a family to move from relative wealth to relative poverty,"<sup>72</sup> the issue of deprivation is arguably of particular relevance in the case of CLHA. In the case of the children at SCH in general, and those with a single parent or both parents in particular, socioeconomic deprivation, or the presence of other serious obstacles to healthy development are not only likely, but inevitable. Indeed, they are prerequisites for admission to SCH. This is since many of the children are brought forward for admission through NGOs that seek out "the most vulnerable and disadvantaged children among the infected children in the area."<sup>73</sup> Moreover, the Home's policy is that "preference will be given to orphans," and that "children of single parents and children living with parents will be considered only after assessing the family condition..."<sup>74</sup>

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<sup>69</sup> So strong is the stigma that one extensive study found that even negative children with positive mothers are often barred from school in a number of Indian districts. See UNICEF (2007) Barriers to services for children with HIV positive parents, p.8 [online] Available at: [http://www.unicef.org/india/The\\_Barrier\\_Study.pdf](http://www.unicef.org/india/The_Barrier_Study.pdf)

<sup>70</sup> See, for example, Save The Children (2009). Keeping Children out of Harmful Institutions: Why we should be investing in family-based care. The Save The Children Fund (2009) [online] Available at: [http://www.savethechildren.org.uk/sites/default/files/docs/Keeping\\_Children\\_Out\\_of\\_Harmful\\_Institutions\\_Final\\_20.11.09\\_1.pdf](http://www.savethechildren.org.uk/sites/default/files/docs/Keeping_Children_Out_of_Harmful_Institutions_Final_20.11.09_1.pdf),

<sup>71</sup> For more about NIOS see <http://www.nos.org/>

<sup>72</sup> Nostlinger, C. et al. (2006). Children and adolescents living with HIV positive parents: Emotional and behavioural problems. *Vulnerable Children and Youth Studies*, April 2006; 1(1): 1-15. Routledge, 20, p. 11 [online] Available at: <http://dSPACE.itg.be/bitstream/10390/945/1/pp2006vcys0029.pdf>

<sup>73</sup> Ibid.

<sup>74</sup> For more on the significant obstacles faced by those with HIV positive parents in Karnataka see UNICEF (2007) Barriers to services for children with HIV positive parents [online] Available at: [http://www.unicef.org/india/The\\_Barrier\\_Study.pdf](http://www.unicef.org/india/The_Barrier_Study.pdf)

Table 2: PCG Income

Child	PCG family monthly income in rupees	PCG family daily income in rupees	Notes
1	1 000		
2	1 500		
3	1 000		
4	Not specified		Elsewhere in file described as “poor”
5	4 167		
6	Not specified		Occupation: coolie
7	Not specified		Elsewhere in file described as self-employed and does not work regularly
8	Not specified		SCH staff says income sufficient
9	2 000		
10	2 500		
11	1 500		
12	3 000		
13	2 000		
14	Not specified		SCH staff describe as “poor”
15	650		
16	400	Also receives daily wage – amount not specified	
17	Not specified		This is the only child for whom (as of May 2012) SCH has not been able to find a PCG
18	1 000		
19	Not specified		Elsewhere in file states that PCG is supporting 7 people in house and wife unaware of child’s HIV status
20	1000		
21	2 500 – 5 000		
22	1 000		
23	500-1 500 (1 000)		
24	Not specified		PCG is a well-off stepmother but cannot keep child as family doesn’t know about now-deceased father’s extra-marital affair which led to child
25	1 000		
26	2 000		
27	Unemployed		50 rupees per day; sometimes no income at all as per Psychosocial Assessment Form
28	2 000		
29	4 000		
30	600		
31	1 000		
32	Not specified		Elsewhere in file PCG described as not financially stable to take care of child
33	2 000		
34	1 000		

Child	PCG family monthly income in rupees	PCG family daily income in rupees	Notes
35	5 000		
36	Not specified		Agricultural background. Staff says poor
37	Not specified		Elsewhere in file described as self-employed and does not work regularly
38	2 500		
39	20 000		Uncle businessman but doesn't want to keep child at home
40	2 000		
41	3 000		
42	1 500		
43	Not specified		SCH staff says PCG is poor
44		100	As per Psychosocial Assessment Form
45	3 300		
46	2 000		
47	Not specified		Described in file as "poor"
48	7 000		Joint family so not a high salary
49	2 000		
50	1 000		
51	1 500		
52	2 000		
53	2 000		
54	1 000-1 500 (1 250)		
55	1 000		
56	Not specified		PCG (uncle) is described as "middle class". Visits etc but chooses not to keep child – staff indicates may be for status reasons
57	Not specified		PCG indicates financial problems as reason for sending child to SCH in Psychosocial Assessment Form
58	1 000		
59	3 000		
60	2 000		
61	Not specified		PCG indicates financial problems as reason for sending child to SCH in Psychosocial Assessment Form
62	7 000		
63		50	
64	1 500		
65	2 000		
66	1 000		
67	1 000		
68		40	
69	2 000		
70	8 00		
71	2 000 - 3 000 (2 500)		As per Psychosocial Assessment Form
72	8 000 - 10 000 (9 000)		
73	1 500		
74		50	

Child	PCG family monthly income in rupees	PCG family daily income in rupees	Notes
75	1 500		
76	2 000 - 6 000 (4 000)		
77	500-1 500 (1 000)		
78		100	
79		50	
80	Not specified		Grandmother PCG - coolie worker
81	2 000		
82	4 167		
83	Not specified		Mother works at CCC and stays there
84	4 500		
85	900		
86	2 000		
87	1 500		
88	1 500		
89	3 000		
90	5 000 - 6 000 (5500)		
91		50	
92	1 500		
93	2 000		
94		50	
95	3 000		
96	1 000		
97	5 000		
98	1 500		
99	1 000		
100	10 000		

(Source: Sneha Care Home & Shining Star School Application Forms - unless otherwise indicated)

Note

- Where yearly income was given this was converted into a monthly rate for uniformity.
- For daily wages this conversion was not carried out since some daily wage earners work a seven-day week while others do not.
- Where the income was not specified in the form, other information was sought, including PCG occupation listed and SCH staff members' written comments in children's files. Where neither of these was available, the author sought verbal comments from SCH staff.

Breakdown of figures

*Of the 100:*

- 19 did not specify their income, 1 was unemployed and 1 PCG earns both a monthly income of 400 rupees and a daily wage of an unspecified amount.

*Of the remaining 79:*

- 8 are daily wage earners whose average wage is 53.75 rupees a day.

*Of the remaining 71\*:*

- 19 earn 1 000 rupees a month or less
- 27 earn 2 000 rupees a month or less
- That is, 65% of those whose application form clearly states that they are employed and includes their family's monthly income earn a monthly salary of 2000 rupees or less.

*\* 71 is the number of PCGs whose child's application form clearly states that they are employed and includes their family's monthly income (or yearly income converted to monthly income by this paper's author).*

## Family involvement in children's care at SCH: Practical policy initiatives

"I will always be in contact with the child and the institute and will extend my utmost support and co-operation for the well being of the child."

(Statement from consent form which primary caregivers are required to sign upon their child's admission to SCH)

### Part of the process?

All the procedures involved in children's care at SCH – including the documentation such procedures involve – have been recorded in a manual. A careful look through this manual reveals all the ways in which families are formally involved in the care process at SCH.

All cases of PCG involvement that appear in the manual have been extracted and listed below. They have been grouped under one of five headings based on the nature of involvement they denote.

The five headings are:

- a. Data gathering (i.e. simply gathering information about the child's family background from the PCGs themselves or otherwise);
- b. Opportunities for contact between child and PCG;
- c. Opportunities for contact between SCH staff and PCG;
- d. Opportunities for feedback from PCG (whether of a decision-making kind or otherwise).
- e. Opportunities for direct involvement of PCG in child's care

There is necessarily overlap between one heading and another. For example, "Direct PCG involvement in child's care" would also fall under "opportunities for contact between PCG and child" and vice versa. This was done consciously in order to highlight certain distinctions. A weekly phone call would be considered contact, taking the child home for a month would also be contact but the latter places the PCG in much more of a direct caregiver role than the phone call. Similarly, data gathering from PCGs can also be considered as PCG feedback or an opportunity for contact between SCH staff and the PCG – but the latter two are meant to denote something more than this.

Unless indicated, the below are direct excerpts from SCH's process documentation manual. The term "family" rather than PCG is frequently used. This is since, as it was pointed out earlier, 99 of the current 100 children have PCGs who are relatives, while staff is in the process of tracing a family member for the remaining child.

Any comments made by this paper's author are preceded by "Author's note."

### *Data Gathering*

"When a child is admitted to SCH, family details and some information pertaining to the child is collected from the parents, family member or guardian of the child. Later, according

to a structured format, the child's initial information is tracked. In the same way, counselling department meets the kids on an individual basis and collects complete information from the child as well as parents or guardians on their visit to SCH. The elaborative profiles are also documented in a structured format."<sup>75</sup>

"Data about the child's family is taken through unstructured interaction with the family member and is recorded in a structured form. Unstructured interaction is applied because it is observed that the structured interaction output is not that effective as they tend to hide some of the facts. It provides an opportunity for parents/ guardians to share their experiences and concerns."

"... [Once the child arrives for admission with the primary caregiver...] The basic interaction pattern is observed in the child [by SCH's counselling Department]. This gives a clear picture of a child's attitude, confidence level and relationship with the primary caregiver. Then some initial interview questions are asked to the child and the responses are noted down. In the same way, some questions regarding the child and his behavioural pattern are asked to the parent/ caregiver/ ORW. The information collected and the observations made are then documented... Rationale: the way a child interacts with the caregiver/ parent/ guardian/ ORW is different from the way the child interacts with new people."<sup>76</sup>

[Author's note: There are 20 questions asked during the child's "intake interview" looking at everything from the child's relationship with teachers, academic progress, religious affiliation to early developmental events (eg bed wetting, stammering, temper tantrums), coping with stress and problems...The families feature directly in the following questions (nos.15-20):]

15. Economic status of child's family
16. Details and child's relationship with parents and any sort of early separation from them
17. Pattern of reward and punishment from them
18. Any sort of abuse
19. Relationship with siblings and who was favoured more
20. Substance abuse in the family<sup>77</sup>

[Author's note: The below are questions from the "Evaluation Questionnaire for CLHIV" selected for their relevance to family involvement]

#### I Programmatic Knowledge

1. Why didn't you join in your local school while your brother/ sister/ neighbours joined there?

#### IV Family

1. What did your parents/ relative/ guardian tell you regarding your health?
2. What did your parents tell you about admission in this school?

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<sup>75</sup> Ibid. p 36

<sup>76</sup> Sneha Care Home and Shining Star School Process Documentation (n.d.) p. 29

<sup>77</sup> Ibid. p 38

3. After holidays we had an evaluation to see how you were at home. Why did we conduct that?
4. Did you experience any discrimination at home at any level?

#### V General

5. Have you noticed that many children don't have parents here? What do you think about it?<sup>78</sup>

#### *Opportunities for contact between child and family member*

“During the time of admission, the families are clearly informed about their contact with the child through phone calls and family visits. These connections are made so that the child does not feel she/ he is abandoned by the family and made clear to the child it is for a purpose that he/ she lives here. Phone calls are requested to be made at least once weekly, timing between 8pm and 9pm on weekdays and 9am to 9pm on Sundays.”<sup>79</sup>

[Author's note: calls made between 9am and 4pm are answered by staff members in the office. Calls made between 7:30pm and 9pm will be answered by children. Each time a call is made this is noted as a way of tracking the level of contact between families and children. Unless the child seems visibly distressed, staff will not ask about the content of the conversation]

“Family visits to the centre are encouraged if they can afford the travelling expenses. When they visit they are asked to sign the visitor's book in order to keep record of the person who visited and their frequency of visit... During their visits they are requested to bring handful of snacks not bulk snacks as upsetting for those whose parents do not visit them often.”<sup>80</sup>

#### *Opportunities for contact between staff and PCG*

“Outgoing calls are made for: Children who do not receive the calls at least once in a month and an enquiry is made for the reason of not making the call; Children who ask for a phone call if have not received for two weeks; For behavioural concerns; Every month the families are being communicated with about the child's positive behavioural change; During birthdays if the child has not received a call.”<sup>81</sup>

[Author's note: Outgoing calls (staff/ child to PCGs) take place Monday-Sunday between 4pm and 6pm.]

“A parents' meet is organised on the day of departure [of the child for his/ her holiday with the primary caregiver]. It provides parents/ guardians with informal opportunities to spend time with staff members and other parents. The main focus is to give an orientation about the programme's functions and its activities, importance of parental involvement in child's life

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<sup>78</sup> Ibid. pp 50-53

<sup>79</sup> Ibid. p 68

<sup>80</sup> Ibid.

<sup>81</sup> Ibid.



through family contacts, sharing of their concerns and holiday details are filled... Holiday details include name and relationship of the person with the child, address and contact number, date of departure and date of arrival and their signature. Once they reach home they are expected to make a call so as to confirm that they have reached their destiny and after a week a call is made to know the child's well-being."<sup>82</sup>

*Opportunities for feedback from PCG (of a decision-making nature or otherwise)*

"The Strengths and Difficulties Questionnaire (SDQ) is a brief behavioural screening questionnaire about 3-16 year olds... It was administered along with Rutter questionnaires to parents and teachers of children drawn from psychiatric clinics. A focus on strengths as well as difficulties; better coverage of inattention, peer relationships and prosocial behaviour are its salient features. Moreover it has a shorter format; and a single form suitable for both parents and teachers, thereby increasing parent-teacher correlations. It is done once every six months by the teacher and care-giver and with the help of parents."<sup>83</sup>

[Author's note: While it has a structured format, there is the possibility (for both parents and SCH) to add other comments or concerns to the SDQ questionnaire]

[Author's note: while the intention is to involve family members in the SDQ questionnaire, this has not been done to date]

"Feedback from parents/ guardians is gathered at the drop-in time of the child to the centre after holidays. Post holiday assessment with the family is done so as to scrutinize the versions given by the child and the family [child also provides feedback]. In case the child is brought through other person, the feedback is gathered through phone call (see appendix ---)<sup>84</sup>

*Opportunities for PCG to assume a significant caregiver role*

[Author's note: the following statement is included in the consent form primary caregivers have to sign upon the child's admission into SCH:] "I also agree that child would be sent home during the holidays and it would be my responsibility to take the child home and bring the child back to the centre."<sup>85</sup>

"Children are sent for holidays twice a year but it is an obligation to take the child for holidays at least once a year... Before the child is sent for holiday a pre-holiday assessment is done... Two rounds of calls are made to the family for taking for holidays."<sup>86</sup>

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<sup>82</sup> Ibid. p 69

<sup>83</sup> Ibid. p 37

<sup>84</sup> Ibid. p 70

<sup>85</sup> Ibid. p 71

<sup>86</sup> Ibid. p 69

## Discussion

### *Staff attitudes to PCG involvement*

SCH staff members' survey responses (see Appendix 4) and individual interviews showed staff attitudes toward children's PCGs to be broadly positive – with the latter being seen as an important ally for the child's development.

What emerged clearly was a sense that having PCGs on board was beneficial to the child and, as a result, made the staff's work easier too. As one staff member put it in an interview: "It really helps if parents cooperate regularly... it makes a real difference, it makes things much easier. Lots of issues can be solved like that. For example, if a child doesn't get calls you will notice behavioural changes – [the] child won't do what we ask, won't study..."

Moreover, there seemed to be little of the "blame and shame" that characterized much of the earlier (and arguably still characterizes some) approaches to the families of institutionalized populations – where families are seen as "the problem" and children put into institutional care to free them of this "polluting" influence.<sup>87</sup>

### *Data gathering*

The tendency to eschew judgment or blame may be at least partly attributable to SCH's policy of collecting family data – which is extensive; reflecting the belief that "[t]o know a child it is important to know his/ her family."<sup>88</sup>

In interviews with the Social Care Department reference was regularly made to a number of families' specific cases and their unique challenges.

One data collection exercise which appeared to be particularly powerful in this respect was the recently introduced one of home visits – where an SCH staff member – accompanied by a district-based NGO worker - visits a number of families' homes while the children are there during their one month holiday in May.

"The home visits were not like an interview. We were flexible – we adapted to how comfortable PCGs were. So, for example, we kept our questionnaire hidden if we noticed that they were less comfortable – and wrote the report after," says one SCH staff member in an individual interview.

It was evident from a number of the interviews conducted for this paper that these home visits contributed to a level of sensitization amongst SCH staff. When it was pointed out to them that certain PCGs did not call their children frequently or rarely visited, for example, staff members often replied with comments such as: "that child comes from a very difficult background. His uncle cares, but he works all day, is paid very little and that makes visiting a

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<sup>87</sup> De Salvatore & Rosenman, 1986; Vander Ven, 1991; Whittaker, 1979 cited by Mikkelsen, E.A. (2010) An Evaluation of a Physical Activity-Based Residential Treatment Program (Utah State University, 5-1-2010; Thesis), p. 20 [online] Available via <http://digitalcommons.usu.edu/>

<sup>88</sup> Ibid. p 68

challenge,” or “her grandmother forgets due to old age” or “his mother isn’t educated, so sometimes we have to remind her to phone on birthdays.” Having experienced some of the more remote villages that some children hail from, one staff member explained to the author that the health complications that sometimes arose when children went home for holidays were often to do with hygiene problems of the area as opposed to familial neglect. This point was echoed during the parent meet evaluation,<sup>89</sup> in which staff members raised the issue of advising caregivers on what eatables to bring their children at the Home (the point was brought up in light of a recent case where one mother brought her child a drink which was shared amongst a few of his friends, resulting in those children contracting Hepatitis A). The Home Visits initiative is discussed in greater detail in section 5.

It might be hypothesized that data gathering which involves placing staff members in families’/ PCGs’ environments in a non-threatening manner might have particular benefits for staff sensitization that cannot be gained from traditional form-filling methods of data collection. Research into whether or not this is the case is beyond the present paper’s scope, yet is worthy of future study.

#### *Opportunities for contact between child and PCG*

There are two SCH staff members dedicated to facilitating contact between children and their PCGs. Their work ranges from working with community-based NGOs to trace PCGs (virtually always a family member unless impossible) to ensuring ongoing communication between PCGs and children during the latter’s stay at SCH.

Clearly stipulated calling times, as well as a policy of making an outgoing call to PCGs if they have not phoned their child in fifteen days or when the child requests such a call, encourage, as far as possible, a steady stream of contact between PCGs and children. Since children are made aware of these policies it is arguable that on a psychological level they communicate to the child that SCH is working with, rather than against, PCGs, and may serve to contribute to the child’s sense that he or she is not being held at SCH against the PCGs’ will. In an interview, one staff member commented that those with non-parental PCGs (that is, whose PCGs are extended kin) often need more help to ensure contact is maintained. The staff member indicated an understanding and willingness to put in this extra effort.

During the evaluation of the group meet that took place on 29<sup>th</sup> April 2012, one staff member noted that PCGs were reminded that it was important that they called their children. For a number of caregivers the Social Work Department say they are constantly the ones calling. This is not said in an accusatory tone. The staff member says that the mentality of some PCGs seems to be that since the staff members call, “they [PCGs] just wait for the call.” The staff member said it was necessary to highlight the importance of PCGs taking initiative in this respect.

During the same evaluation it was noted that some PCGs complained that phone calls to SCH were not being picked up. The SCH staff member who brought up this point claimed that this

was mainly when calls were made at inappropriate or inconvenient times. The staff member said PCGs were reminded that it was children who were responsible for answering the phone calls between 7:30pm and 9pm and that they should refrain from calling between 6pm and 7:30pm as this would disrupt the children's schedule (i.e. they should call between 7:30pm and 9pm from Monday to Friday and any time on Saturday and Sunday).

From the data it emerges that regular visits of PCGs to the centre (which exclude the group meets organized on the day of the chi departure for long holidays) were less common than calls. Despite the overwhelming majority of PCG's home districts being a one evening bus journey away from SCH, many SCH staff members indicated, during individual interviews, that financial constraints often prevented such visits. Aside from the travel costs, making the journey and paying the child a visit would mean losing a day's wage. As a number of PCGs are agricultural labourers or engaged in other occupations dependent on a daily wage, this is increasingly unfeasible. Finally, poor infrastructure in a number of the more remote villages makes travelling difficult despite the relatively close distance between said villages and SCH.

#### *Opportunities for communication between staff and PCGs*

It is difficult to know how much phone communication there is between staff and PCGs since the phone call records make no distinction between incoming calls that were for the purpose of talking to the staff member and those for the child.

In the evaluation of the group meet that took place on 29<sup>th</sup> April there was agreement among staff that one drawback of the day was the limited opportunity PCGs had to talk to the staff.

All pointed out that in future more staff should be involved on the day and each given a specific role which would avoid the situation where a small number of staff is overwhelmed with responsibilities with the result that there is not enough time to talk to the PCGs. All agreed that more time was needed for the staff to talk to PCGs. The strong likelihood that such an opportunity would have been welcomed is indicated by the Social Work Department's comment that PCGs "were happy to ask questions."

Yet during the same meeting the staff indicated that such "group meets" were not necessarily the best opportunities for such interaction. The staff all agreed that more individual sessions with PCGs are needed as due to the logistical challenges of organizing and coordinating such an event as well as the staff's point that PCGs are often in a hurry to make their journeys back, "things are always rushed at these meetings." This was both when PCGs are taking children for holidays as well as when they are bringing them back to SCH.

#### *Opportunities for PCG Feedback*

PCGs' opportunities for feedback are mainly through post-holiday questionnaires which ask a set list of questions while allowing for the PCG's own comments. Phone calls and visits to SCH also grant caregivers' the opportunity to provide feedback however as noted previously, such calls are unfortunately impossible to track using the existing data and visits are difficult for a number of PCGs.

During the evaluation of the 29<sup>th</sup> April meet, the main feedback noted by a staff member was a mother's comments about the children's hygiene. "Whenever I come I see them shabby" was her feedback. She made plans to return to SCH to have a follow-up meeting with the Social Work Department to discuss this further.

While a suggestion box was introduced to give PCGs an opportunity to provide anonymous feedback, only two PCGs made use of it. Staff agreed the main problem was that many of the PCGs did not know how to write. Clearly, opportunities for oral communication between staff and PCGs are crucial.

### *Opportunity for PCG to assume a significant caregiver role*

All SCH children are encouraged to go home to their PCGs twice a year. The first is a short holiday lasting ten days and is optional. The second, which is a one month holiday over the Month of May is obligatory, barring health or other serious complications on the part of PCGs.

Outside of the context of children's holidays, the opportunities for PCGs to take on a direct care-giving role for the child might be considered to be somewhat limited.

Moreover, the SCH staff's replies to the attitudes survey clearly indicate that while staff members showed a broadly and overwhelmingly positive attitude toward parent involvement, they were more supportive of involvement that put PCGs in a learner/ helper role rather than a decision-making, empowered role.<sup>90</sup> The sense amongst one staff member is that PCGs are not really seeking a more empowered role in the SCH programme but are more interested in spending time with the child. The question "Do you wish for the PCG to be more involved in the [SCH] programme?" was put directly to the SCH staff member during an individual interview for this paper. The reply was "No. PCG's don't want to be more involved in the programme – more involved with the child yes." The extent to which this is in fact the case is difficult to verify without speaking to PCGs directly.

The role of PCGs seems to be more in appraising the programme (mainly through the post-holiday feedback form) rather than having a say in its design – though it is arguable that if appraisals raised concerns that were acted upon, primary caregivers would have indirectly played a role in the programme's design. During the 29<sup>th</sup> April meet evaluation meeting one staff member mentioned that a parent complained about the children's standard of Kannada (the language spoken in Karnataka) being poor. A second staff member replied by saying it needed to be explained to parents that Shining Star School was an English medium school. A third staff member countered this last point saying it was important that the issue of Kannada was looked into. It was unclear at the time of this paper's writing, however, whether this would translate into any tangible initiatives.

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<sup>90</sup> Interestingly, the study from which the survey used in the present paper was taken found similar results amongst its respondents. See Baker, B.L. et al. (1998). 'Staff Attitudes toward Family Involvement in Residential Treatment Centers for Children' in A compendium of Articles from Psychiatric Services and Hospital and Community Psychiatry. American Psychiatric Association (1998)

Asked whether SCH might consider introducing more or longer holidays, in reaction to a number of such requests from PCGS the three staff members interviewed individually all showed reluctance. One staff member said this was for two reasons: the first was that such visits would disrupt children's structured programme and the second was to do with fears over potential medical complications caused by the hygiene and nutrition situation at their homes. The staff member recalled the case of one child who "had been doing well here" and then suffered complications and passed away during her one month period at home. This sense of fear that "home" could be a dangerous place did not appear to be shared to the same extent by the other two staff members interviewed. One said "we have to do a lot of work when they come back... but it's worth it." The third staff member also said more, or longer, visits were not likely to be introduced but indicated that this was for practical reasons rather than a sense of fear – saying it would "disrupt their [the children's] programme."

To be sure, there are barriers to PCGs taking on an empowered role that have nothing to do with staff attitudes or policies. Research has found that socioeconomic levels and travel distance are significant determinants of family involvement in children's out-of-home care.<sup>91</sup> Given the low socioeconomic status of many of the PCGs of children at SCH, and the difficulties involved in travelling from some of the more remote villages in Karnataka, this has significance for the case of SCH. Indeed, it was already noted that many PCGs find it difficult even to manage regular visits to SCH. Moreover, a number of PCGs have very limited or no educational background whatsoever which is likely to make them hesitant or unsuitable candidates for mapping out children's educational programme at SCH.

### *The benefits of empowered PCGs*

Given the available evidence on the potential benefits of such PCG empowerment,<sup>92</sup> it might be worth finding realistic, practical and case-specific niches for PCGs to demonstrate such empowered caregiving – either through more opportunities for direct caregiving of the child or by being involved in the SCH programme in some decision-making capacity.

It should be pointed out, however, that evidence of the benefits of "empowered caregiving" come from studies that place "family reunification" as their central goal.<sup>93</sup> As discussed earlier in the paper (chapter 2, p. 15) this goal may at certain points conflict - or at least exist in a tense relationship - with the vision at SCH.

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<sup>91</sup> Baker, B.L.; Blacher, J. And Pfeiffer, S. (1993). Family Involvement in Residential Treatment of Children with Psychiatric Disorder and Mental Retardation. Psychiatric Services, Vol. 44, no. 6. Though strongly emphasizing that the institution's policies matter, another study concluded that amongst other things, "[p]erceived parental resistance or reluctance to participate in their child's treatment may be reframed as a need for resources to pay for transportation..." amongst other things (Kruzich, J.M. et al (2003). Family Caregivers' Perceptions of Barriers to and Supports of Participation in Their Children's Out-of-Home Treatment. Psychiatric Services (2003) Vol. 54 (11: 1513-1518) [online] available at: <http://ps.psychiatryonline.org/data/Journals/PSS/3601/1513.pdf>)

<sup>92</sup> See, for example, literary review provided by Mikkelsen, E.A. (2010) An Evaluation of a Physical Activity-Based Residential Treatment Program (Utah State University, 5-1-2010; Thesis), especially p 23 [online] Available via <http://digitalcommons.usu.edu/>

<sup>93</sup> See for example Martone et al. (1989)'s "Engagement-Participation-Empowerment-Discharge" model [online] Available at: [http://www.tandfonline.com/doi/abs/10.1300/J007v06n03\\_03](http://www.tandfonline.com/doi/abs/10.1300/J007v06n03_03)

### *The issue of capacity*

What at first glance may appear to be limited opportunities for PCGs' empowered involvement in SCH may, however, be misleading. Certainly, SCH's "Keep the parents alive" policy – which networks with NGOs to ensure infected parents of the children under its care receive adequate medical care and supervision is a form of "empowering" PCGs. Moreover, even if the ultimate goal is for parents to take on a more active caregiving role toward the child, this might at times necessitate placing them in a "learner" role first. When the children were collected on 29<sup>th</sup> July for their one month holiday, for example, part of the programme organised by SCH staff was reserved for talking about ART medication adherence, personal hygiene, the importance of eating home-cooked rather than store bought food and of giving the child clean boiled water rather than juice, amongst other things. In this case, "teaching" PCGs did not preclude the latter's possibilities for empowered caregiving, indeed it positively facilitated it. In their interviews, SCH staff members maintained that their links with NGOs help to promote as far as possible, benefits such as access to ration cards and employment for a number of the family members of children under their care. They also claimed that children's family members approach staff on a number of occasions seeking legal advice – and staff put them in touch with a legal representative or organisation working to provide that service. Director Fr Mathew argues that it is useless talking about "empowerment" before such basic services are met. "The issue of empowerment," he says, "has to be linked to capacity."

### *From 'empowerment' to 'partnership'*

Rather than "empowering" family members, the focus, Fr Mathew insists, might be more usefully shifted to "partnering" with them. The importance of institutions involving family members as active partners in the care process has been recognized in the case of Alzheimer's patients.<sup>94</sup> In practice, developing a partnership with family members would mean drawing on the extensive knowledge and insight of the family member and creating an inviting atmosphere for them to visit. It would also mean being receptive to family feedback and concerns – and making listening to family members a priority. It would include discussing ongoing concerns related to the child with his or her family member and keeping the care process "open" to scrutiny and suggestion from family members. The good news is that such practices can be measured. Opportunities for feedback can be quantified, contact between child and family members and between family members and staff can be tracked, qualitative methods can be used to determine the extent to which the child's family member views the Home as inviting and staff as receptive. Barriers to partnership: from attitudinal barriers of staff and family members to more tangible barriers such as travel costs for family members can be identified and addressed. Relatively straightforward policies can be adopted to ensure that the "partnership" between family members and institutional staff is real and meaningful, rather than an empty promise – a hollow buzzword.

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<sup>94</sup> 'Remembering4you: in giving care or receiving support after a diagnosis of Alzheimer's or memory loss.' See especially section on institutions partnering with family caregivers [online] Available at: <http://www.remembering4you.com/index.html>

## Siblings

### *Why focus on siblings?*

Having a healthy relationship with a sibling – particularly an older sibling who is HIV negative - is arguably of particular importance for CLHA as even CLHA whose parent(s) are alive are sadly never freed from the spectre of orphanhood. The increasing reality of sibling-headed households in a number of HIV-affected communities<sup>95</sup> demonstrates just how crucial it is to factor siblings into models of care for CLHA.

### *Keeping Siblings Together*

Table 3 lists the number of biological and non-biological siblings of individual children at SCH. SCH policy is in line with best-practice guidelines that state that, as far as possible and beneficial, siblings should be kept together. As it is SCH policy that only sero-positive children are admitted, the policy of keeping siblings together is not extended to negative siblings. In practice this also means that there are currently no non-biological siblings at SCH, since at present, none of these non-biological siblings are known to be HIV positive.

For the sake of clarity, it is useful to think of there being 83 children at SCH – with the remaining 17 being siblings to 16 of those 83 children (See Appendix 3). As expected, all 17 are HIV positive. At the time of writing this paper, there were 4 children who were HIV positive siblings of children at SCH and were not also at SCH. The reasons are summarized in Table 4 below.

Table 3: Siblings of children at SCH

#### **Biological siblings**

Total number of siblings	122
Siblings at SCH	17
Siblings not at SCH	105
Total number of siblings who are HIV Positive	21
Number of HIV Positive siblings not at SCH	4
Total number of Negative siblings	101
Total number of children at SCH who have a biological, elder, negative sibling	63

#### Note:

- One younger, biological sibling in doubt about HIV status (included in statistics about siblings but not in those distinguishing HIV status).

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<sup>95</sup> Save the Children UK (2001). Children Affected by HIV/ AIDS: Rights and responses in the developing world, Working paper no. 23, p. 32 [online] Available at: [http://v2.ovcsupport.net/libsys/Admin/Documents/Children\\_Affected\\_by\\_HIV\\_AIDS\\_Rights\\_and\\_Responses\\_in\\_the\\_Developing\\_World\\_1.pdf](http://v2.ovcsupport.net/libsys/Admin/Documents/Children_Affected_by_HIV_AIDS_Rights_and_Responses_in_the_Developing_World_1.pdf)



### Non-biological siblings

Total number of non-biological siblings	10
Non-biological siblings at SCH	0
Non-biological siblings not at SCH	10
Total number of non-biological siblings who are HIV Positive	-
Number of non-biological HIV Positive siblings not at SCH	-
Total number of Negative siblings	7
Total number of children at SCH who have a non-biological, elder, negative sibling	2

Note:

- 3 non-biological siblings have an unknown HIV status. They are non-biological siblings to 5 of the children at SCH and are younger than all of them. The number of non-biological HIV positive siblings and/ or negative siblings listed would change accordingly.

Table 4: HIV positive siblings not currently at SCH

1	14 years old – making her/him ineligible to enter SCH (must be aged 4-10)
2	3 years old – making her/him ineligible to enter SCH (must be aged 4-10)
3	16 years old – making her/ him ineligible to enter SCH (must be aged 4-10). This child was admitted into Sneha Southern in Mangalore when sibling was admitted into SCH. The 16 year old child has now returned to family
4	The PCG said she would wait to see how the child currently at SCH was doing before deciding whether or not admit the child’s sibling into SCH. So far the PCG has not requested this admission

*Sibling connection*

As shown in Table 3, there are 105 siblings of children at SCH who are not also living at SCH. In interviews, SCH staff claimed to have the contact numbers of 103 of those siblings – and to be working on getting the contact details of the remaining two. All 10 non-biological siblings are in touch with their at-SCH siblings.

There is currently no specific formal procedure for maintaining sibling contact at SCH. Nevertheless, elements of such a procedure exist since sibling contact falls within the procedures of maintaining child-PCG contact. Staff members explain that when calling PCGs

the child usually speaks to his or her sibling also as the 103 siblings with whom SCH staff are in touch all live with PCGs - except one who lives in a hostel. Interestingly, the child who lives in a hostel had no contact with her sibling until the latter was admitted into SCH. SCH's Social Care Department staff worked to put the siblings in touch with each other and they are now in regular contact. The out-of-SCH sibling staying at the hostel is both elder than the at-SCH sibling and is Negative.

SCH Social Care Department staff indicated to this author that sibling contact is encouraged and that staff members regularly make contact with children's siblings as the latter do not tend to make phone calls to children at SCH without this push from the staff's end.

At the time of this paper's writing, the Social Care Department reported two cases of obstacles to creating contact between at-SCH and not-at-SCH siblings. These are the two siblings referred to in the opening paragraph of this section. In one case, the not-at-SCH sibling had been adopted and the adoptive mother was averse to such contact - since the child's adoptive status would become known as a result. In the second case, the out-of-SCH sibling was informally adopted by extended kin who were not the PCG of the child at SCH. In this case the PCG claims that the extended kin were blocking contact. The Social Care Department staff said that they were currently looking into both cases.

#### *Specific concerns related to negative siblings*

To view siblings of CLHA – and Negative siblings in particular – purely as a support resource would be to ignore the significant challenges that beset this particular population – challenges that often not only limit their potential to in fact provide such support but can and often do seriously hamper their own development.

A UNICEF study on barriers to services faced by this population found that in Karnataka, affected children are frequently victims of exclusion within their communities. At school many face “mistreatment by teachers... are made to sit separately, [and] get less attention than their classmates,” amongst other things. The study also found that “some schools bow to public pressure to refuse admission to affected children.” In Karnataka specifically the children interviewed for the study “referred to the impoverishment of their families due to HIV/ AIDS.” The study also found that many affected children face barriers to even routine medical services or are denied them altogether because “it is assumed they are HIV positive.” In Nagaland and Maharashtra, affected children reported barriers to food aid or subsidised food stuffs.<sup>96</sup> Moreover, there is evidence that affected girls may be especially badly hit. While orphanhood is debilitating for both boys and girls, the tendency for girls to assume more of the domestic responsibilities means affected girls' education is likely to suffer.<sup>97</sup>

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<sup>96</sup> UNICEF (2007) Barriers to services for children with HIV positive parents, p.8 [online] Available at: [http://www.unicef.org/india/The\\_Barrier\\_Study.pdf](http://www.unicef.org/india/The_Barrier_Study.pdf)

<sup>97</sup> Ledward, 1997 cited in Save the Children UK (2001). Children Affected by HIV/ AIDS: Rights and responses in the developing world, Working paper no. 23, p. 29 [online] Available at: [http://v2.ovcsupport.net/libsys/Admin/Documents/Children\\_Affected\\_by\\_HIV\\_AIDS\\_Rights\\_and\\_Responses\\_in\\_the\\_Developing\\_World\\_1.pdf](http://v2.ovcsupport.net/libsys/Admin/Documents/Children_Affected_by_HIV_AIDS_Rights_and_Responses_in_the_Developing_World_1.pdf)

Perhaps unsurprisingly given such obstacles, one study found that HIV positive parents reported an “elevated level of behavioural symptoms in [their] HIV-affected children.”<sup>98</sup> As poverty is strongly correlated with HIV/ AIDS, it has been noted that affected children face an increased risk of becoming destitute, getting involved in criminal activity and are especially vulnerable to sexual exploitation and other forms of abuse.<sup>99</sup>

### *A fledgling sibling programme*

SCH describes its vision as being that of “bringing the siblings in” to the care process. In various direct and indirect ways, negative siblings are already beneficiaries of SCH services. SCH’s “Keep the parents alive” policy works to ensure medical support for their parents, thereby reducing their care burden. Like PCGs, affected siblings are connected to the NGOs with which SCH is linked and can use such connections to access basic services like ration cards and employment schemes. Moreover, Fr Mathew says that it is hoped that by easing the burden of caring for CLHA, they will be freeing up caregivers to care for their affected siblings – who may otherwise have been neglected given the pressures involved in caring for the ill child. At the time of writing this paper, plans were being made to adopt and apply many of the procedures currently used for children’s PCGs to out-of-SCH siblings. From data collection – including documenting affected siblings’ education levels, which of them work, how much they earn and their marital status – to organising “sibling meets” – inviting siblings to SCH for a day of activities. Director Fr Mathew says there is an additional benefit to be accrued from the “bringing siblings in” policy. As mother-to-child transmission rates continue to decline, future beneficiaries of SCH are increasingly likely to be affected and not infected children. In that sense, the sibling programme becomes a window into the complex, often hidden reality of this vulnerable population.

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<sup>98</sup> Nostlinger, C. et al. (2006). Children and adolescents living with HIV positive parents: Emotional and behavioural problems. *Vulnerable Children and Youth Studies: An International Interdisciplinary Journal for Research, Policy and Care*, Vol. 1 issue 1 [online] Available at: <http://www.tandfonline.com/doi/abs/10.1080/17450120600659036>

<sup>99</sup> Save the Children UK (2001). *Children Affected by HIV/ AIDS: Rights and responses in the developing world*, Working paper no. 23, p. 29 [online] Available at: [http://v2.ovcsupport.net/libsys/Admin/Documents/Children\\_Affected\\_by\\_HIV\\_AIDS\\_Rights\\_and\\_Responses\\_in\\_the\\_Developing\\_World\\_1.pdf](http://v2.ovcsupport.net/libsys/Admin/Documents/Children_Affected_by_HIV_AIDS_Rights_and_Responses_in_the_Developing_World_1.pdf), p. 35

## Blending institutional and community care

“When people ask us: ‘When do you integrate the child into the community?’ we find this to be a very strange question. We are integrating the child into the community all the time.”

(SCH Director, Fr Mathew Perumpil)

The image of the institution as a segregating form of care, cutting members off from their communities and undermining their possibilities for forming meaningful social ties is not entirely unwarranted. Staff members’ fear of what might happen to the vulnerable children under their care – which is born of their own disconnection from the children’s communities – leads to policies which further disconnect them and the children under their care from those communities. It is a vicious circle.

In reaction to hearing that one nun from another institution opposed sending children home because they came back malnourished and ill, SCH director Fr Mathew said “Yes, they do – check on them, follow up... it’s not a reason not to send them.”

The ability to check on and follow up children while at home is largely the result of close ties between SCH and Karnataka’s CCCs that have been fostered over the years. It is to this which the paper now turns.

*CCCs/ NGOs/ PLHA Networks: SCH’s “extended arms”*

Under India’s National Aids Control Organisation (NACO), **over 300 (check)** Community Care Centres (CCCs) were set up with the aim of providing community outreach and ensuring accessible support and health care for PLHA. Most CCCs are faith-based – and their roles include providing medical care, forms of counselling, psychosocial, educational and nutritional support, linking individuals to ART centres and tracking drug adherence, among other things. Moreover, they help in day-to-day issues like ensuring vulnerable families have ration cards and access to the job market as well as providing vital outreach services for the community. Like many, SCH Director Fr Mathew argues that CCCs should eventually be mainstreamed, but that there is a need to build the capacity of public hospitals before that can be achieved. In the interim, CCCs and similar NGOs have played and continue to play a pivotal role in ensuring medical access and social support for PLHA in the community.

Between 2006 and 2011, the USAID (United States Agency for International Development)-Samastha programme became a catalyst for increasing the number of CCCs in Karnataka (there were previously ten). The role of the Sneha Care Team within this programme was that of a mentor, offering a supportive role to the Centres. In that sense, SCH and Karnataka’s

CCCs were intricately linked from the very outset to an extent which, it is arguable, may not be easily replicable.

With time, SCH's links with CCCs have been strengthened (see Appendix 5). While the majority of the community-based organisations SCH works with are CCCs, they are also linked to NGOs and PLHA Networks in a number of districts. In previous sections and hereafter, "NGOs" refers to any of these three.

Even prior to the child's admission, the Sneha Care Team and NGOs act synergistically, as NGOs are mainly responsible for identifying the most vulnerable CLHA and bringing them and their parents or caregivers to SCH's attention. The children at SCH all hail from Karnataka and almost all their native districts are a one-night bus journey away from SCH.

Once a child is accepted into SCH, working with NGOs – mainly their counsellors, outreach workers and project coordinators - enables the Sneha Care Team to cultivate a vital link between the institution and the child's community. For starters, NGOs are an integral component of SCH's "Keep the Parents Alive" policy, which supports parents of the CLHA under its care. SCH checks up on the health situation of positive parents by keeping in touch with NGOs and on a number of occasions itself refers parents to NGOs when concerns about their health or socioeconomic well-being arise.

Moreover, NGOs act as SCH's "extended arms" directly during the two sets of holidays that are part of children's annual programme. Regular contact with NGOs enables SCH to keep tabs on things like drug adherence and facilitates access to PCGs if these are unreachable.

#### *Home Visits: Taking the institution to the community*

"Most of the cases really surprised me... Before visiting I couldn't imagine what a remote village was like. There was no infrastructure... I saw twenty-four people on a rickshaw [which seats a maximum of three people]... they have no alternative. The hygiene situation was also really poor... there were no toilets... I could see why some children at SCH are not receptive to our initiatives. It was a good learning experience for us."

(Programme Coordinator, SCH)

SCH introduced "home visits" in 2011. A "home visit" is when an SCH staff member – accompanied by an NGO worker - visits a number of PCGs' homes while the children are there during their one month holiday in May.

When it was suggested that such visits might reasonably be seen as an imposition or invasive by caregivers, the near unanimous reply across SCH staff members' individual interviews was that the mere presence of a NGO staff member – with knowledge of the particular family and community dynamics as well as rapport with the family member – could effectively counter that perception. It was insisted at various points that the purpose of these visits is less to "check up" on the child than to provide its staff members with an insight into the child's background.

To date, SCH staff members have jointly managed to cover 80 percent of children's PCGs' homes. Staff members typically spend a maximum of thirty minutes in each house, though there is no set time. The idea is to collect basic data, including an assessment of PCGs' economic situation and to get a feel of the children's backgrounds and communities. Home visits were also introduced with the aim of linking children to NGOs if no prior connection existed and identifying secondary caregivers for children.

In cases where the child's HIV status had not been disclosed to extended kin living nearby or to the rest of the community, SCH staff explained that they presented the visit as a routine house call by teachers of the child's boarding school: a discussion and assessment of the child's academic performance. During an individual interview with this author, SCH's Programme Coordinator explained that on more than one occasion PCGs appeared to derive a sense of "happiness" from these visits – appreciating that staff took the trouble of going to their (mostly very modest) homes.

#### *The Kolar Outreach Programme: Bringing the community to the institution*

The Kolar Outreach Programme is an interesting example of how the institution may be uniquely placed to spearhead community-based initiatives.

In 2011 SCH established an outreach programme in the Kolar district in conjunction with the SCH-owned CCC 'Sisters of Precious Blood.' SCH's stated aim for setting up this outreach programme was to address the complex needs of some of the community-based siblings of the children under its care and to provide services for other infected and affected children within the community. Drug adherence and medical support is a fundamental part of the programme – since it was only through the SCH-owned CCC 'Sisters of Precious Blood' that a section of the district hospital was developed to cater for the needs of CLHA. Before this initiative, the public hospital in Kolar did not have a specific programme for the medical care of CLHA. Yet the stated rationale behind the programme is that national services for CLHA focus overwhelmingly on their medical care – meaning that issues such as their education, eventual employment and the successful negotiation of adulthood are treated as secondary or not addressed at all. It is these areas which the outreach programme is particularly geared toward,

The outreach programme covers fifty infected and two hundred affected children in Kolar. The idea is to ensure they have access to the basic services they are entitled to and that they are receiving ongoing medical and social support to meet their needs in the present. Beyond that, the stated goal of SCH is to "accompany these children in their journey towards the future." To that end, Fr Mathew's vision is also to absorb these children into "Phase Two" of SCH which was being developed at the time of this paper's writing: the vocational training institute for CLHA aged 13 or over. "To recognise their aptitude and develop their skills... and make them independent citizens of the country."

Setting off this outreach programme was a camp that SCH organised in 2011: a camp for CLHA in Kolar district which was held at SCH itself with the assistance of experts from NIMHANS (National Institute of Mental Health and Neuro Sciences) and St. John's Medical

College, Bangalore. The aim was for it to serve as a comprehensive needs assessment camp “aimed at evaluating and seeing whether their [the children’s] clinical, psychological, social and educational needs are addressed appropriately or not.”

In 2012, a second summer camp was organised with these children. As the children are monitored throughout the year by Sisters of Precious Blood – with one of the CCC’s personnel specifically being responsible for going to the children’s homes - it is through her that SCH coordinates the camp. Transport is freely provided.

When the Kolar children come to SCH for this one-week summer camp, staff say the idea is for them to interact with one another, form friendships and enjoy themselves. It also serves as a crucial opportunity for children to be checked by on-site medical personnel and to go to the hospital (mainly St. John’s Medical College, Bangalore) for any check-ups or tests that need doing. A nurse working for Sisters of Precious Blood who was present at the camp explained to this author that many of these tests were not available at the hospital in Kolar.

The Kolar initiative is one powerful example of how institutions can use their expertise to develop outreach programmes that identify and address service gaps in community-based care. SCG not only collaborates with the CCC – but was responsible for its establishment and continues to be responsible for its funding. SCH director Fr Mathew says that the hope is to develop similar outreach programmes in the future.

## Conclusion

The primary purpose of this paper has been to use the case study of SCH as a springboard to challenge the paradigm that presents “family” and “community-based care” as antithetical to institutional care. Both in its vision and through a number of the practical policy initiatives highlighted, SCH challenges the “either-or” approach to the long-term care of vulnerable children – and CLHA specifically – and encourages us to think of blended models of care.

Viewing institutions as part of a blended model of care has implications for funding. Fund “either” this “or” that does not make sense within the framework of a *good* blended model in which institutions trace, cultivate and support familial ties rather than weaken them, network with community-based initiatives rather than compete with them and, conversely, where regular, sustained and meaningful familial and community involvement make the care provided by the institution more holistic and ultimately more effective.

Just as there is danger in allowing the anti-institutional mantra to become an ideologically entrenched position, an uncritical acceptance of institutions carries serious risks. The fact that a number of institutions can be harmful to those under their care has been well-documented. Yet a blanket condemnation of institutional care is hardly the solution. In fact, the precise opposite may be true. By taking an anti-institutional stance officials have, in many ways, effectively allowed institutions to operate unchecked – since funding and monitoring frequently go hand-in-hand. This is certainly not to the benefit of seriously deprived children – who overwhelmingly continue to reside in institutions.

Indeed, recognising this reality, and appreciating that institutions may in fact be the best option for some children, particularly in some places such as India where certain factors may militate against the feasibility of the proposed alternatives, a number of authors pushing alternatives have emphasized the importance of clearly established and enforced guidelines for “good-enough” institutions.<sup>100</sup> While ensuring minimal standards of institutional care is a crucial first step, the suggestion running through this paper is that by thinking less monolithically about institutions, less rigidly about care models and more creatively about the potential for synergy between family, community and institution – we can, perhaps, be even more ambit

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<sup>100</sup> See, for example, Tolfree, D. (1995). *Roofs and Roots: The Care of Separated Children in the Developing World*. Save the Children Fund, UK (1995), p. 81 [online] Available at: <http://www.crin.org/docs/roofs%20and%20roots.%20%20the%20care%20of%20separated%20children%20in%20the%20deve.pdf>



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