Palliative Community Resource Centres

Brief description
DPH currently has 3 Palliative Community Resource Centres (Butterfly Houses) situated within the economically most depressed regions of the sub-district. The focus of the palliative community resource centres is to address community transformation which includes hope for prosperity, health and wellness in the future.

Background (which led to the decision to implement this best practice)
Traditionally Hospices have focused on caring for patients with a life threatening illness and an expectation of dying. HIV/AIDS, escalating chronic illnesses, poverty, poor health literacy, high levels of neglect, abuse, teenage pregnancies and hopelessness encouraged DPH to find alternative culturally sensitive ways of approaching 'living' with a life-threatening illness and life limiting condition. Care in the community, by the community, with the community became and mantra and 'Hope has Wings' our approach.

In 2009 we opened Butterfly House in Fairyland, then an informal settlement and the only brick building in the surrounding area. *Our response came from questioning how we could assist parents: to live with HIV; provide healthy, happy prosperous homes for their children, and to embrace life and living when they have had the expectation of dying?* How could we do care with and not for people, acknowledging challenges but also tremendous resources within the communities where we work? How could we ensure that children infected and affected by a life-threatening illness would have the opportunity to approach life and living in a positive, skillful and hopeful way?

In 2012 we opened iBhabhathane (Butterfly) in Mbekweni and in 2014 we started programmes at Tiffany's in Paarl East. These last two programmes are specifically focused on our referred children, infected and affected by life-threatening illnesses or life-limiting conditions.

Purpose of the best practice
'The need is too big and too complex to do alone', therefore partnerships are essential and our focus is specifically on providing quality interventions to the most vulnerable. *Therefore we have an admission process and have developed specific programmes which focus on life skills, support and recreation, education and health literacy in a holistic manner.* Former and current co-ordinators have been a social worker, pastoral therapist and occupational therapist with a professional nurse acting as manager.

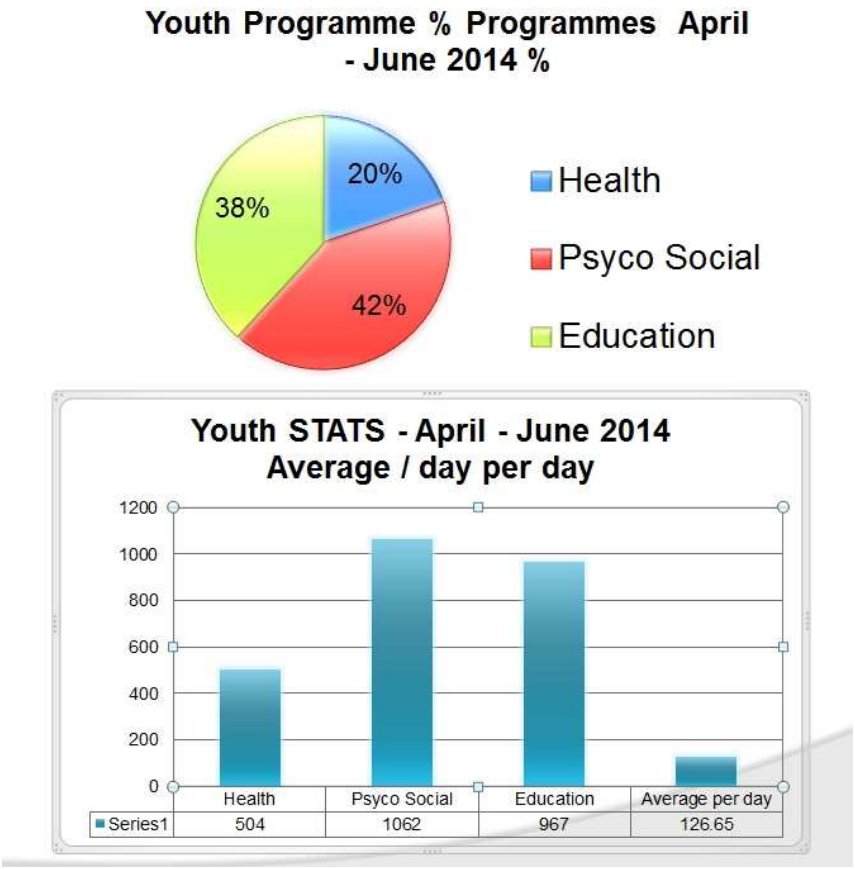
Challenges which emerged
- Funding has been the greatest challenge but also the greatest inspiration and motivation. Providing a quality service in a well maintained infrastructure has been key to on-going support.

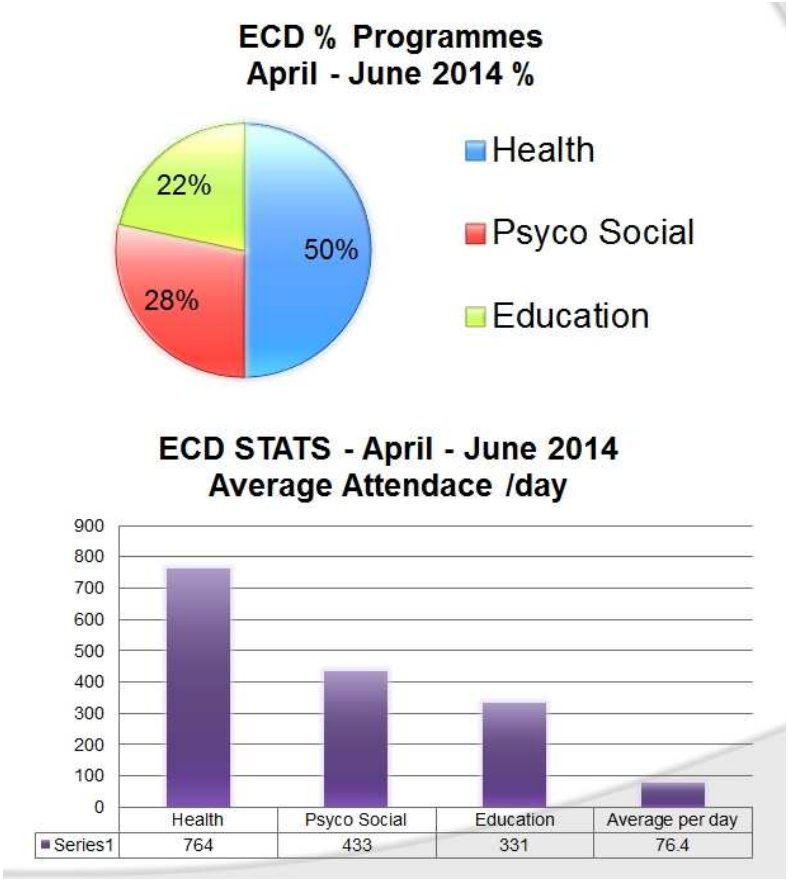
- Providing care in the community, by the community, comes with built-in challenges to security and lack of resources, skills and qualifications. On-going promotion and training has largely mitigated this threat.
- The non-African approach and funding focus on quantity has often tripped us up as it is usually numbers that speak the loudest. An effort to protect the service delivery from these demands has spurred us to find competencies and capabilities within communities that are utilized and showcased, resulting in an adjustment of the external focus on numbers.
- Finding ways to assess outcomes, which are qualitative, has been a challenge. We have designed our own tools which have not been verified but nonetheless serve to guide the quality and nature of our interventions.
- Our growing awareness and knowledge of community and individual needs has at times been overwhelming. We constantly need to find innovative, creative and sustainable ways of continuing the service in the face of financial constraints. (See our Community Support Worker Programme)

Method used

- This is a transdisciplinary model of care which acknowledges that skills and capabilities exist within communities that do not necessarily look familiar or are acknowledged as valuable by the disciplines working in the field. Therefore community consultation, participation and involvement is essential to relevant successful interventions.
- The programmes originate from a sound theoretical framework which includes palliative care, feminist theology, justice and medical ethical principles. This is a holistic, non-religious approach that advocates for people with disabilities or who have been disadvantaged for whatever reason (physical, social, emotional, cultural, spiritual or knowledge). The medical ethical principles of autonomy, beneficence, maleficence and justice guide the approach that the patient/client is the head of the team and the expert of their own lives. We therefore do care with people and not for.
- Cross-cutting principles have been devised which guide interventions. These outcomes give direction and something to work towards. They are autonomy, self-confidence, personal capacity development, justice and ethics and gender fairness. They originated from the work of Wangari Maathai, (2004 Nobel Peace Prize Laureate) and her book; 'The challenge for Africa' (2009). These principles are tried and tested and have served us well and have only become stronger and have gained greater significance.
- 'The need is too big and too complex to do alone', has ensured that we engage partnerships and share ownership. The DPH role is to create and maintain the philosophy of practice and infrastructure and ensure sustainability and relevance.

The impact made by the best practice





- These programmes have ensured that we are part of prevention and promotion of health and wellness and are part of creating a hopeful future and community transformation.
- Doing care in the community, by the community, with the community has enabled us to provide appropriate, culturally sensitive care to adults and children, infected and affected by a life-threatening illness or life-limiting condition.

The way forward

- To continue to investigate, ask questions, do research and publish findings and learn from experiences and interactions.
- To continue to include the community in care provision and as cultural consultants and to promote and share best practices.
- To ensure sustainability through remaining relevant and working towards aligning our work with the approach and needs identified by the Department of Health and Social Development.
- To continue to invest in the staff and community through on-going education, training and mentorship in order to develop their personal capacity, self-confidence and accountability and adding to quality care provision.
- To hold ownership lightly of the projects and to share knowledge and resources that will benefit the community and our patients.
- To ensure quality service provision that addresses the needs of our patients, our children and our community.
- To remain respectful and adjust to clients changing needs remembering that the patient/client is the head of the team.

Conclusion

Palliative community resource centres have supported and enriched the service provision of Drakenstein Palliative Hospice. It has enabled us to support holistic health and wellness of the most vulnerable people in our community. It has supported job satisfaction and community transformation, it is about 'doing hope'. It is about helping people, help people.

See our YouTube clip: http://www.youtube.com/watch?v=Rvepe7jhWxw