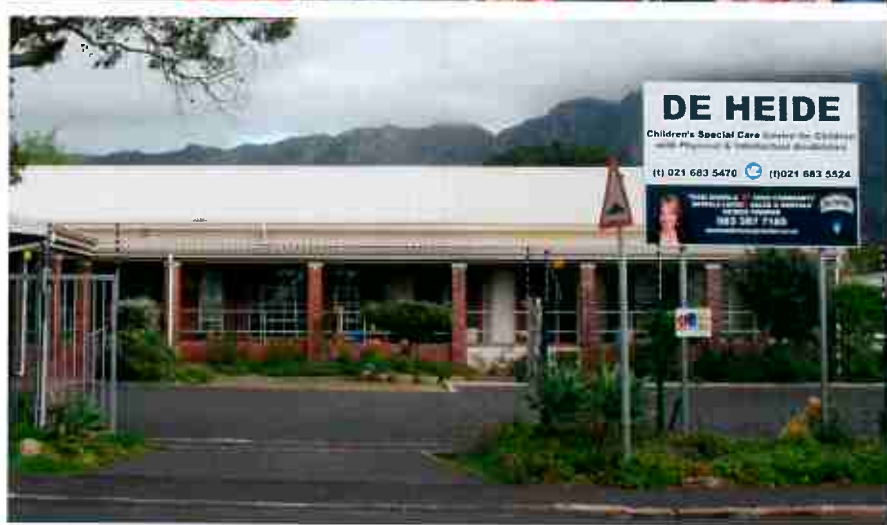




The VILLAGE

WORK Centre



THE WESTERN CAPE CEREBAL PALSY ASSOCIATION **ANNUAL REPORT 2017/18**

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Chairperson's report

Seeking to serve the needs of our clients is at the heart of everything we do. This is only possible with the dedication of our board members, staff and generous donors.

Working on the ongoing tasks of serving the needs of our clients can sometimes be so consuming that we forget to remind ourselves of our achievements. But as we look back on the year that has been, the board of the Western Cape Cerebral Palsy Association (WCCPA) is confident that the organisation continues to meet these client needs and remain focused on keeping these clients at the heart of everything we do.

One such achievement is the 50-year-long unique partnership between the WCCPA and the Red Cross War Memorial Children's Hospital. In this partnership the WCCPA, through the support of its donors, has been providing specialist rehabilitative therapy to children with cerebral palsy at the hospital since 1968. While the nature of the partnership

has changed and developed over the years, 2017 saw us reach a significant milestone with the signing of the first Memorandum of Agreement between the WCCPA and the hospital.

The launch of the Assistive Buddies programme at our protective employment workshop has been another achievement where affordable assistive devices for people with disabilities are being produced by people with disabilities. The enthusiasm with which workers with disabilities at our protective employment workshop embarked on this project is promising for the future of the programme.

During the past year we spread our wings as the WCCPA developed partnerships with community-based organisations in rural towns of the Western Cape. In doing so, we are able to provide access to specialised rehabilitative services to children with

cerebral palsy.

While our challenges are ever-present, the most significant being the water crisis in Cape Town that saw our residential facility Rosedon House under the greatest threat of Day Zero with 57 residents with cerebral palsy being completely reliant on the WCCPA for their care. While the Day Zero crisis in Cape Town has been averted, we are still working toward finding a sustainable water management solution for Rosedon House as environmentalists predict a dry future for Cape Town.

We look forward to moving from strength to strength and leveraging the valuable partnerships we have already established to be able to continue with our client-centric approach in service delivery

M.N. Osman Chairperson

TRIBUTE

Dr Leila Arens

A pioneer and visionary in the treatment and care of children with cerebral palsy.

Since 1968 the Western Cape Cerebral Palsy Association (WCCPA) has been providing rehabilitative therapies to patients at the Red Cross Children's Hospital (RCCH). The significance of this 50-year partnership is that it was started when the field of Developmental Medicine and Child Neurology was in its infancy internationally. The WCCPA Cerebral Palsy Clinic at RCCH was started by Dr Leila Arens and Dr Gladys Beinart. Sadly, Dr Leila Arens recently passed away at the age of 97 years and it is with deep gratitude and pride that the WCCPA pays homage to Dr Arens.

Dr Leila Joan Arens (Silber) passed away peacefully on 8 July 2018 in Minnesota in the USA. She was born

in Johannesburg in 1921 and spent most of her life in Cape Town before emigrating to the United States to join her children in 2001. She graduated as a medical doctor from the University of Cape Town and spent most of her professional career as a physician, studying and caring for children with cerebral palsy. She published many studies on these topics and pioneered several novel therapies designed to improve the quality of life of the children she treated. She taught many generations of medical students and was known for her excellent teaching.

The WCCPA Board, Management, Staff and Service Users extends sincerest condolences to the Arens/Silber family.



De Heide Annual Report 2018

"It is necessary to adopt a holistic approach for severely or profoundly disabled children, to enable them to develop their ability and potential to the fullest extent" *Professor Chris Moteno – Emeritus Professor, Dept Psychiatry and Mental Health UCT*

De Heide Special Care Centre is a day centre that provides a care and educational programme for children and adults with severe and profound physical and intellectual disabilities and who experience severe barriers to learning.

Children with Severe or Profound Intellectual Disability function at the lowest levels of development in the conceptual, social and practical domains. Despite their significant developmental delays, they are still able to learn daily routines and aspects of self-care, albeit in different ways to children without disabilities. The main focus at De Heide is aimed at learners becoming as independent as possible, and as such, the activities in the education programme are selected to meet this aim. The activities are

presented through interactive learning encounters to create a fun and enjoyable learning experience. Despite the children acquiring a level of independence, the reality remains that they will always require a great deal of care and supervision throughout their lives.

De Heide offers a structured developmental programme and individual support plan which includes:

- Ongoing assessment to ensure that the appropriate education and development programmes are implemented
- Individual therapeutic interventions and correct positioning to prevent impairment progression and complications
- Activities of daily living
- Training for parents and caregivers to ensure continued management

in the home environment

- Education and training for staff.
- Social Work support to parents of children at the centre and in the home
- Daily transport

Over and above the education programme, De Heide continues to participate in lobbying and advocacy initiatives in respect of the rights of people with intellectual disabilities from awareness raising, influencing legislation and information sharing.

Despite the difficult circumstances and challenging economic times that many non-governmental organisations and civil society face, De Heide has been able to remain steadfast in its quest for a better life and service for children with multiple disabilities.



Our Hope Community Day Programme

Loneliness and social isolation can affect anyone, but people with disabilities are more vulnerable to it than others.

Occasionally feeling isolated is normal and part of being human. Sadly, for many people with disabilities that feeling is not an occasional experience; for many people with disabilities, feeling isolated and lonely is the norm.

For people with disabilities the isolation is largely the result of negative public attitudes, prohibitive access to community and public facilities, and a lack of suitable transport. Even those living with their families are more likely to be excluded from social activities outside the home which then leaves them homebound. The provision of the WCCPA Day Programme for adults with disabilities allows them to participate in meaningful occupational and socialisation to avoid deterioration of their disabilities.

School leavers with Cerebral Palsy (CP) from schools for Learners with Special Educational Needs, who are not admitted to Protective Workshops for People with Disabilities, remain at home without any meaningful occupa-

tion and interaction with people other than their immediate families. This after spending many years fully integrated in a school environment. The Day Programme was initiated to provide these school leavers with an opportunity to participate in occupational and socialisation activities and learn new skills which would contribute to their health and well-being.

The need has also arisen to provide a Day Programme with the objective of providing occupational and socialisation activities for adults at the Association's Protective Workshop. As adults with cerebral palsy age, their func-

tioning deteriorates and they are no longer able to participate in the work activities at the Protective Workshop. The provision of a Day Programme will ensure that adults with disabilities, who can no longer cope with the activities at the Protective Workshop, are not excluded and left isolated in their homes.

They will remain in a familiar environment and still interact socially with their peers. Experience over the past two years has shown that when people stopped attending the Protective Workshop their level of functioning deteriorated rapidly.



Rosedon House

Navigating the effects of aging on top of living with disabilities as adults with cerebral palsy are living longer.

Recent medical advancements have increased the life expectancy for adults with cerebral palsy (CP) to roughly the same age of the general population. This development raises questions about how to best manage the effects of aging on top of living with a disability, especially as adults with cerebral palsy are prone to premature aging.

Premature aging is thought to be the result of a lifetime of physical impairment that places extra stress and strain on the bodies of people with CP to complete everyday tasks. Research shows that from about 30 years old, most adults with cerebral palsy will experience some form of premature aging in either or both their physical and intellectual functioning.

The majority of residents at Rosedon House were first admitted in the early 1990s. Currently residents have an average age of 51 years and the majority present with conditions related to premature aging, which continues to increase the burden of care at Rosedon House

Rosedon House, a residential facility for adults with cerebral palsy (CP), was opened in 1990. This, after the WCCPA identified the need for residential services for persons with cerebral palsy who were no longer able to live independently or with their families or who no longer had a family of origin. Adults at Rosedon House come from communities across the Western Cape and have varying degrees of CP.

Rosedon House provides accommodation in a secure environment adapted to the special physical needs of the residents like adaptations to bedrooms and bathrooms. In addition, residents are provided with a supervised nutritional diet and specialised transport to



public health facilities.

Residents who are able to work at a protected workshop, attend the Village Work Centre and those who are not attend the Our Hope Occupational Group.

The Clinical Management Team at Rosedon House develops a care and rehabilitation plan in consultation with residents and their families to ensure that they maintain optimal functioning in interaction with their environment. Premature aging results in high care needs for almost all the residents at Rosedon House and brings with it the realisation that without the care and rehabilitation they receive at Rosedon House their health and well-being will deteriorate to the point that they will have to be hospitalised or institutionalised impacting on their right to a good quality of life.





The Village Work Centre

Creating safe and reliable work for people with disabilities as we continue to foster the holistic development of our clients.

The Village Work Centre (TVWC) recently launched a project called Assistive Buddies where workers in the woodwork department of TVWC manufacture low-cost assistive devices for people with disabilities. Access to assistive devices increases the quality of life of people with disabilities.

While assistive devices are available at retail medical outlets, the costs are prohibitive to people with disabilities reliant on government disability grants. These devices are rarely provided to people with disabilities in the public health system and are only accessible to people with medical aid and higher personal income. The Assistive Buddies are actively marketed to health professionals in public health facilities in communities in Cape Town to ensure

that the targeted population of people with disabilities have access to information about the devices. The interest in the devices is encouraging as more people with disabilities will have access to assistive devices which will improve their quality of life. Interest in the assistive devices has also been shown by older persons, stroke patients, patients recovering from surgery as well as people suffering from osteoarthritis. An added positive outcome of this programme is the employment opportunity for school leavers with disabilities who did woodwork as a subject.

TVWC is a protective work centre for adults with CP and other disabilities who are unable to be employed in the open labour market. In addition to manufacturing assistive devices, work-

ers at TVWC undertake packaging and labelling for businesses in and around Cape Town. Teams of workers are supervised by TVWC staff who are trained in managing people with disabilities. A functional assessment of the workers on admission to TVWC followed by work skills training ensures that they are assigned work tasks appropriate to their level of functioning. In addition, workers receive life skills training which focusses on activities of daily living and functioning.

Work is regarded as important in structuring daily life, enabling a sense of continuity and as an antidote against boredom and emptiness. While this is often quoted for the general population, it is no different for people with disabilities.

Social work annual report 2018

“We must see to it that we remove the obstacles for people with disabilities, whether they stem from poor access to facilities, poor education, lack of transport, lack of funding or unavailability of equipment such as children’s wheel-chairs.” (Nelson Mandela December 1995)

Obstacles faced by people with disabilities range from access to basic human rights such as accommodation to services like appropriate, safe and affordable transport and access to basic assistive devices. Imagine being a frail 5-year-old girl with severe physical and intellectual disability as well as profound hearing loss. Now imagine caring for this little girl and her two siblings in a backyard dwelling, which floods completely when it rains on the Cape Flats. This family’s first housing application to the City of Cape Town was submitted in 2011 and social workers at the WCCPA have been assisting the family since 2013 to access adequate accommodation.

Representations included medical

reports and strong recommendations from the girl’s doctors as well as video footage of the family’s appalling living conditions. The polite but curt response from the City of Cape Town’s Housing Allocations Committee is that “the family will have to wait their turn”.

The National Department of Health committed to free access to assistive devices for people with disabilities in 2003, yet as late as 2017 our social workers assisted a 12-year-old girl who was still waiting for a wheelchair a year after being placed on the waiting list at a Provincial Hospital.

In the meantime, her family borrowed a wheelchair which only has one footrest and one side that is loose and dislodges when she leans against it. The borrowed wheelchair is

not just uncomfortable and unsafe it is also causing further deformities to her spine. The WCCPA social workers continually make representation to local and provincial government departments to assist families with these kinds of challenges. In addition, social workers provide the following services:

- Support to parents of newly diagnosed children with cerebral palsy.
- Assist families with the appropriate placement at day centres, LSEN schools, protective workshops and residential placements.
- Develop support services for people with cerebral palsy through collaboration with health and social development practitioners in the communities.

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THE WESTERN CAPE CEREBAL PALSY ASSOCIATION

The Western Cape Cerebral Palsy Association is extremely grateful to all our loyal donors for financial support, many donations-in-kind and all the voluntary services we have enjoyed during the past year. Your support enabled the association to provide vital services to children and adults with cerebral palsy.

Provincial Government of the Western Cape

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Department of Social Development

International funding

Australian High Commission Direct Aid Programme

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Gift of the Givers
New Apostolic Church Youth
The Grey Ladies
Wynberg Rotary Club

*It's what difference we have made in the lives of others that
will determine the significance of the life we lead*

NELSON MADELA

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