

Oct / Nov 2009

VOICES OF CHANGE



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Transformation for PEOPLE with disabilities

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WAKE UP! ALCOHOL KILLS YOUR UNBORN BABY

Drink
while
pregnant?
Think
again!

Prof. André J. Claassen

A mother's alcohol use during pregnancy is one of the top preventable causes of birth defects and developmental disabilities. There is no known amount of alcohol that is safe to drink while pregnant. There is no time during pregnancy when it is safe to drink. When a pregnant woman drinks alcohol, her baby does too. Fetal alcohol spectrum disorders (FASDs) is the name given to a group of conditions that a person can have if that person's mother drank alcohol while she was pregnant. These conditions include physical and intellectual disabilities, as well as problems with behaviour and learning. Often, a person has a mix of these problems. FASDs are a leading known cause of intellectual disability and birth defects. The good news is that FASDs are 100% preventable—if a woman does not drink alcohol while she is pregnant. ■



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Hearing Screening is "Cool"



Prof. André J. Claassen

The tragedy of the young deaf baby is difficult for an adult to truly understand. A child who is born with a severe degree of deafness or who becomes deaf in early childhood and is not managed appropriately, will not learn to talk and is therefore not only deaf but also dumb. They also do not develop inner speech which forms the basis of our thought processes. When we think we formulate our thoughts and ideas into words and sentences. Therefore loss of inner speech can impact on the child's intellectual and emotional development.

So how does speech develop? The normal baby can hear sounds even from the time before birth. Babies do not understand the sounds initially, but because of their special aptitude during

especially the first year of life to distinguish sounds it develops meaning to them. The first year of life is the so-called period of READINESS TO LISTEN and is an extremely important period in the development of hearing. Then follows the period of readiness to speak 12-18 months.

The developing baby realizes the significance of sounds and also that they themselves can produce sound. The latter is possible if they have hearing, because if they cannot hear the sound that they produce it will have no meaning to them. They soon realize that the sounds that they produce can illicit reaction in their environment e.g. mothers footsteps when they cry etc.

The ideal situation for a baby is to be close to its parent's with love and security, being well fed and cared for. A mother can use up to 305 words per half hour when busy with a baby perhaps sitting on her lap close to her. This ensures a continuous source of stimulation which optimizes the process of learning to hear.

Under normal conditions a baby will have heard the word mamma 20 000 times before being able to say it himself. This emphasizes how complicated it is for a normal hearing baby under ideal circumstances, to learn to say the word mamma for the first time. This might take a year or even more. How difficult is it then for a hearing impaired baby to learn to do the same?

This emphasises the need to diagnose hearing impairment as early as possible. The earlier that management is started, the better the outcome. The larger majority of hearing impaired babies can be rehabilitated either by supplying strong hearing aids or by doing a cochlear implantation. The tragedy of a late diagnosis is



that rehabilitation can become impossible. The baby is most receptive to learn how to hear and then to speak during the first 3 years of his life. From there on it becomes more difficult and later on impossible. Therefore the window of opportunity is a critical period in the young child's life. The brain, if not stimulated by sound in the first 3-4 years of life loses its ability to learn how to hear and then to speak.

What causes deafness in early childhood?

Fifty percent of early severe childhood hearing loss is due to genetic factors. Researchers are studying the genetic factors responsible and significant progress is being made. This, however, emphasises the importance of a family history

which might be regarded as a risk factor.

The second big group of causes of early childhood deafness is the acquired one. Together these 2 groups result in profound hearing loss in 1-8 per 2000 births.

In the next edition we will discuss some of these causes and also how early deafness can be diagnosed. ■

Tahlehelo ya kutlo, boqhwalala bo tlwaelehileng haholo



Prof. Riaz Y. Seedat

HTshebetso e ka sehloohong ya setsebi sa tahlehelo ya kutlo ke ho ntlafatsa kutlo le bokgoni ba puo ho ya nang le tahlehelo ya kutlo.

Batho ba bangata ba hodileng ba na le tahlehelo ya kutlo. Leha feela motho qalehong a na le bothata ba ho utlwa medumo e hodimodimo, mme o kgona ka ho kopa batho ho pheta seo ba se buileng le ho phahamisa modumo hantle wa seyalemo ya radio kapa TV, tahlehelo ya kutlo ke bothata bo tswellapele le ho feta. E ka ba le boemo bo fokodisang bo lebisang maemong a tlontlolo, pherekano, ho kwekwetla dibaka moo ho nang le batho ba bangata, le ho ba le kगतello ya maikutlo.

Leha tahlehelo ena ya kutlo e hlahela jwaloka karolo e tlwaelehileng ya botsofe, ho bohlokwa hore bakudi ba bothata bona ba hlahlojwe e le ho netefatsa hore sesosa se ke ke sa phekolwa na, jwaloka ho tlosa dikonokono ka tsebeng, ho kwala lesoba moropeng wa tsebe, kapa ho hlokomela bothata bo amang masapo a kutlo. Ha mathata ana a le teng, mme a phekolwa, tokiso e makatsang e ka ba teng kutlong. Ka lebaka lena ho bohlokwa hore mokudi a bonwe ke ngaka, ka ho qolleha e be setsebi sa mahloko a tsebe, nko le mmetso.

Ke hore bakudi ba tshwanetse ho hlahlojwa ke setsebi sa methapo-kutlo, mme se tla etsa diteko tsa kutlo e le ho tseba mofuta le bohoto ba tahlehelo ya kutlo. Sena e tla ba thuso ya ho tseba hore sethusa-kutlo se leng teng, mme se loketse tahlehelo e teng ya kutlo ke sefe. Ha re kgothalletse ho reka sethusa-kutlo ntle le tlhathobo e nepahetseng, ka ha ho ka etsahala hore sethusa-kutlo seo e be se sa lokelang mofuta wa bothata bo leng teng ba tahlehelo ya kutlo. ■

Mohopolo wa sekwalejwale taolong ya bothata ba kutlo maseeng le baneng

Ho thata ho motho e moholo ho utlwisa e le ka nnete masetlapelo a ngwana e monyenyanane ya sa utlweng ka ditsebe. Ngwana ya tswetsweng a na le boemo bo bobo ba bothato kapa eo e bang setholo qalong ya bongwana ba hae, mme bothato bo sa laolwe ka tsela e tshwanetseng; ngwana a ke ke a ithuta ho bua, mme ka lebaka leo e ke ke ya e ba setholo feela empa hape e tla ba semumu. Hape bana ba jwalo ha ba kgone ho buela ka hare e leng se bopang qalo ya tshebetso ya monahano. Ha re nahana, re isa mehopolle le menahano ya rona popong ya mantsele le dipolelo. Ka lebaka leo tahlehelo ya ho buela ka hare e ka ba le tshusumetso e kgahlanong le matla a monahano wa ngwana, hape le ntshetsopele ya maikutlo.

Ka hoo, puo e hola jwang? Ngwana ya phetseng hantle o kgona ho utlwa medumo esita le hoja a so hlahe. Masea ha a utlwisa modumo qalehong, empa ka lebaka la neo ya bona e ikgethang e hlahellang haholo nakong ya selemo sa pele, ba kgona ho kgaohanya medumo, mme e bopa moelelo ho bona. Selemo sa pele sa ho phela se bitswa nako ya BOITOKISETSO BA HO MAMELA, mme ke nako e bohlokwa ka ho fetisisa popong ya kutlo. Ka mora moo, ho latela nako ya boitokisetso ba ho bua: dikgweding tse 12 ho ya ho tse 18.



Ngwana ya holang hantle o elellwa bohlokwa ba medumo, mme hape le hore bona e le bana ba ka kgona ho etsa medumo. Sena se boletsweng se kgonahala feela ha ba na le kutlo, hobane ha ba sa kgone ho utlwa modumo oo ba o etsang, seo se ke ke sa ba le moelelo ho bona. Ba elellwa kapele hore modumo oo ba o etsang o ka etsa ho hong tikolohong ya bona, mohlala: mohato wa maoto a bomme ba bona ha ba lla (bomme ba a ba phallela ha ba lla), j.j.

Maemo a bohlokwa ngwaneng ke ho ba haufi le batswadi ba hae, ho fumantshwa lerato le tshireletso, ho feptjwa hantle le ho hlokomelwa. Mme a ka sebedisa ho fihla mantsweng a ka bang 305 halofong ya hora ha a na le ngwana wa hae, ka mohlomong ngwana a dutse seropeng sa hae. Sena se tiisa

mohlodi o matla o tswellang pele, wa ho fana ka tshepo tshebetsong ya ho ithuta ho utlwa. Tlasa maemo a tlwaelehileng lesea le ka tshwanela ho utlwa lentswe "mamma" makgetlo a ka

bang 20 000 pele le ka kgona ho bitsa lentswe leo. Sena se tiisa taba ya hore ho thata ha kae ngwaneng ya utlwang hantle, ya tlasa maemo a hlokalang, ho ithuta ho bitsa lentswe "mamma" lekgetlo la pele. Sena se ka nka selemo kapa ho feta. Jwale ho thata ha kae ngwaneng ya nang le bothata ba kutlo ho etsa se tshwanang le se etswang ke ya se nang bothata?

Sena se tiisa tlhokahalo ya ho elellwa bothata ba kutlo ka pele ka moo ho kgonahalang ka teng. Ho qala ka nako ka taolo eo, ho ka ba le sephetho se molemo. Bongata ba masea a nang le bothata ba kutlo a ka thuswa mohlomong ka ho nwa dithuso tse matla tsa kutlo, kapa ho ba kenya bokahare ba tsebe.

Masetlapelo a ho elellwa bothata bona ba kutlo ka mora nako, e ka ba hore thuso e ka se kgonahale. Lesea le amohela ho

ithuta ho utlwa ka tsela e batsi, mme ka mora moo le ithuta ho bua nakong ya dilemo tse tharo tsa pele tsa bophelo ba hae. Ka morao ho moo le ho ya pele, ho ba thata haholo, mme ka mora moo kgonahale e ka ba siyo. Ka lebaka leo, nako ya monyetla nakong e hlokolotsi ke bophelong ba ngwana bonyenyaneng. Boko ba lesea ha bo sa hole bo utlwa modumo dilemong tse mahareng a 3-4 bophelong ba lona, le lahlehelwa ke bokgoni ba ho ithuta ho utlwa, mme ha morao ho bua.

Bothato bo bakwa ke eng qalong ya bongwana?

Diphesente tse mashome a mahlano tahlehelong ya kutlo qalong ya bongwana ke a ikarabellang mabakeng a lefutso, mme tswelopele ya bohlokwa e se e entswe. Le ha ho le jwalo, sena se tiisa bohlokwa ba nalane ya ba lelolo, e ka nkwang jwaloka lebaka la tllokotsi.

Sehlopha sa bobedi se sehlo tahlehelong ya kutlo qalong ya bongwana ke sa bana ba amohelang bothata bona (ba bang le bothata ba kutlo ka mora tlhaho ya bona). Dihlopha tsena hammoho di tswala tahlehelo e kgolo ya kutlo e ka bang 1-8 ho 2000 tsa masea a tswalwang.

Kgatisong e latelang re tla buisana ka tse ding tsa disosa tsena, mme hape le ka moo bothato bo ka elellwehang e sa le nako ka teng. ■



Screening for and preventing birth defect



Dr. B.D. Henderson,
Human Genetics, UFS

Birth defects are defined as "any abnormality of body structure or function (can be obvious or hidden) that is present at birth, irrespective of whether the cause is genetic or non-genetic". This definition is very wide and includes many minor variations from normal and all the very serious problems that can be present at birth. It includes birth marks, a curved small finger or a large gap between the great and second toes. These minor changes are usually of no health importance on their own but the presence of a number of them can indicate the presence of a serious (but not necessarily obvious) problem. A major birth defect implies that there will be impairment of normal functioning and/or reduction of life expectancy if they are uncorrected or uncorrectable. These major birth defects include inherited disorders such as Down Syndrome, Huntington's Disease, microcephaly, non genetic disorders such as Fetal Alcohol Syndrome, and a host of other disorders.

Many of these disorders are individually rare but as a

group affect many people. About 1 in 10 people will be influenced by a genetic disorder in either themselves or a first or second degree relative during their lifetime. International figures for the incidence of birth defects are about 6% and just over half of that figure is for major birth defects. The figure for South Africa is unreliable but from the research done it seems to be in the vicinity of 8%, again just over half are major ones. The graphs below are from the World Health Organization and reflect the prevalence of birth defects in different areas of the world and by type.

In the developing nations of the world about 7 million babies are born annually with a major birth defect.

These defects can be caused by many different factors; 15% are due to pure genetic factors (such as a defect in a single gene or a chromosome abnormality), about 10% are due to environmental causes (such as alcohol, drugs or certain medication taken by a pregnant woman or infections during pregnancy), 25% are caused by a combination of genetic and external factor but for the majority we do not know what the cause is.

Much emphasis is placed on preventing birth defects. Treatment is often not available or effective in improving the quality of life for persons affected by these disorders. The first level of prevention is primary prevention and implies that steps are taken to prevent the disorder from developing or occurring in the first instance. Here we are looking at family planning and particularly planning for a healthy pregnancy. This can be achieved by ensuring that the prospective mother is as well as possible. If she requires medical treatment for a chronic illness, she needs to discuss this treatment with her doctor to be sure that it is not harmful to a pregnancy or change to safe medication. Immunization against Rubella before falling pregnant will prevent the disastrous effects of rubella on a fetus. The prospective mother should take folic acid for at least 3 months prior to falling pregnant and continue until 4 months pregnancy duration. All pregnancies must thus be planned particularly when there is a chronic illness.

During the whole pregnancy, a mother must avoid drugs, smoking and alcohol, avoid viral infections as far as possible,

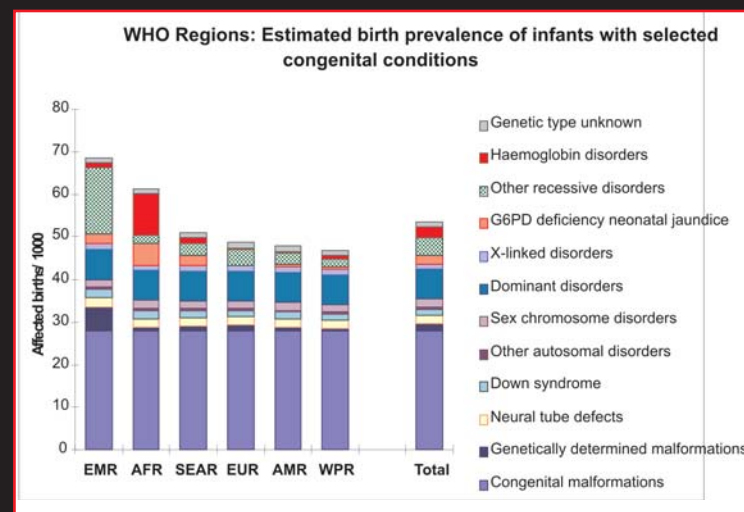
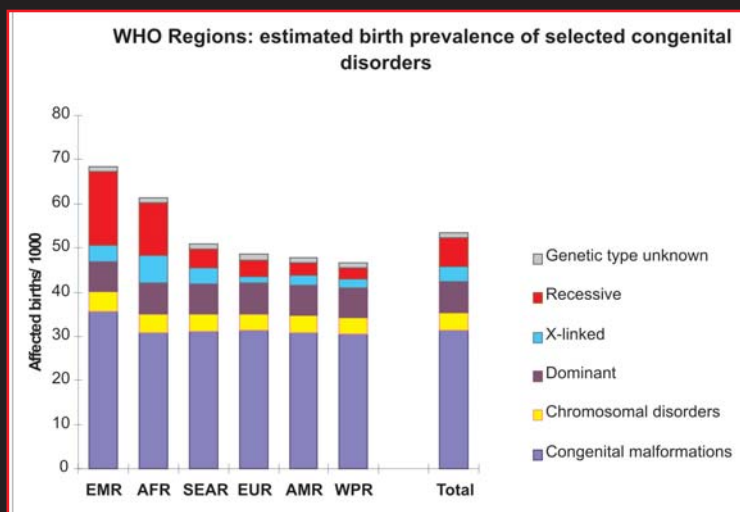
make sure that any medication prescribed is safe for the fetus and regularly attend prenatal care. Prenatal care is for the mother's and baby's health. Antenatal clinics are not to be visited only in the event of a problem or to book a place for delivery in a health care facility.

During the pregnancy certain tests might be recommended to the mother. These tests will be aimed at identifying pregnancies at high risk for problems with regard to the mother's or baby's health. This forms secondary prevention where serious disorders can be identified early and action taken to prevent the birth of a baby with very serious problems or mobilize health care to act early and provide care that will prevent complications.

One group of tests that are offered, are screening tests. A screening test is test designed to identify individuals at higher risk for developing a certain problem. A screening test does not make a diagnosis but only identifies the people at risk and in who a diagnostic test is justified. For example we know that advancing maternal age (over 35 years age) is associated with an increasing risk for the birth of a baby with Down syndrome. Mothers at risk

should be offered amniocentesis as a way to be sure this has not happened and to empower the mother who it has happened to, to take steps acceptable to her to address the event. A large proportion of Down syndrome infants are born to mothers younger than 35 years age. These mothers can be offered nuchal translucency screening by sonar at 11 – 13 weeks and maternal serum screening (blood tests on the mother) at 15 weeks. The results of these tests are subjected to mathematical manipulation and a risk is determined. Depending on the risk, amniocentesis may be offered. Certain combinations of these tests will allow the identification of 90 -93% of all babies with Down syndrome before the halfway stage of a pregnancy. People with a family history of genetic disorders need to obtain specialist information about what can be offered to assist them in preventing a recurrence of the disorder.

An important fact is that screening tests determine risk and do not make a diagnosis. There is always a chance that the tests will not identify everybody with the disorder being tested for.



Thibelo ya bofokodi tlhahong

Ngaka B.D. Henderson, Karolong ya Lefutso Bathong, UFS

Kgatello e kgolo e bewa hodima thibelo ya mefokolo tlhahong, hobane hangata pheko e fumanehe kapa pheko e ka ntshetsang bophelo ba mahlatsipa a mafu ana pele. Boemo ba pele ba thibelo ke ba ho nka mehato ya ho thibela lefu/bohloko ho hola kapa ho ba teng. Mona re shebile therong ya malapa, mme haholoholo re shebile boimana bo phetseng hantle. Sena se ka fihlellwa ka ho etsa bonnete ba hore mme enwa ya lebelletseng lesea o phetse hantle ho ya ka moo ho hlokalahalang ka teng. Ha a hloka pheko e bongaka mabapi le bohloko/lefu le sa pheko leheng, o hloka ho buisana le ngaka ya hae ka sena, e le ho

netefatsa hore bohloko/lefu leo ha le kotsi boimaneng ba hae kapa a ka fetohela phekolong e bolokehileng. Moento wa thibelo ya malwetse kgahlanong le "Rubella" pele mme a ba mmeleng (ho feta dikgwedi tse tharo pele a ba mmeleng), ho ka thibela kodua/kotsi e fetelletseng ya "Rubella" ho lesea le holang ka popelong. Mme ya batlang lesea a ka nka "0.8 mg folic acid" ka letsatsi bonyane dikgwedi tse tharo pele a ba mmeleng, mme a tswellepele nakong ya dikgwedi tse nne a le mmeleng. Ka hoo, ho ba mmeleng ho tshwanetse ho rerwa/hlophiswa, haholoholo mothong ya nang le bohloko bo sa pheko leheng. Batho ba bang ba tla hloka ho sebedisa "folic acid" e ngatanyana hae ba ho na le nalane lelokong ya mafu/mahloko a itseng.

Nakong yohle ya boimana, mme o tshwanetse ho qoba/phema diithethafatsi tsohle, ho tsuba le tahi/jwala, ka moo ho kgonahalang a pheme le dikokwana-hloko tse tshwaetsang, mme a etse bonnete ba hore pheko e nngwe le e nngwe eo a e newang e bolokehile mabapi le lesea la hae le holang ka popelong, mme hape ka mehla a ye sebakeng sa tlhokomelo ya baimana/tlilining. Sebaka sa tlhokomelo ya baimana/tlilini se hlokomela bophelo ba mme le ba lesea. Dibaka tsa tlhokomelo ya batwetse/ditlilini ha di etelwe feela nakong ya bothata kapa ho beelelsa sebaka sa ho beleha feela. Batho ba lelolo le nang le nalane ya mahloko/mafu a lefutso kapa bofokodi tlhahong ba hloka ho fumana keletso ya setsebi pele ba lohotha ka boimana. ■

A Fetus
without
alcohol
grows into
a princess...

... Please don't
drink
smoke
or use
drugs
during your
pregnancy





Werkende honde vir persone met gestremdhede



Prof. Hennie Oosthuizen

Die woord HELP is 'n vierbeenwoord. Wêreldwyd maak gestremde persone van opgeleide honde gebruik as hulp in hul daaglikse lewes. Anders as in party ander lande is daar tans geen wetgewing in Suid-Afrika waarvolgens dienshonde gereguleer word nie. Dit is 'n gestremde persoon se konstitusionele reg dat sy dienshond toegelaat moet word om sy hanteerder na enige plek te vergesel, insluitende restaurante, skole, op busse, treine, vliegtuie, film- en konsertteaters, sportbyeenkomste, doktersprekkamers en enige ander openbare en privaat plekke.

Die Americans With Disabilities Act omskryf 'n dienshond as enige gidshond, seinhond of ander dier

wat individueel opgelei is om werk te verrig of om take te doen tot voordeel van 'n individu met 'n gestremdheid, insluitend maar nie beperk tot gids vir persone met beperkte sig, die waarsku van individue met beperkte gehoor oor indringers en geluide, die voorsiening van minimale beskerming of reddingswerk, die trek van 'n rolstoel, of die optel van artikels wat geval het.

Daar word kortliks na 'n paar kategorieë van werkende honde gekyk:

Gidshonde: Die mees bekende is sekerlik die gidshond wat die oë van sy eienaar is en hom deur die verkeer, trappe en sypaadjies op en af te navigeer terwyl hul struikelblokke wat beserings kan veroorsaak vermy.

'Hearing dogs': Die honde word spesifiek opgelei om dowe persone te help. Hulle waarsku eienaars oor geluide/klanke, gewoonlik deur hul eienaar te nader en dan terug te beweeg na die oorsprong van die geluid. Hulle word geleer om te reageer op deurskietende klanke, telefoon wat lui, rookalarms, huilende babas, klokke van mikrogolfoonde en selfs 'n fluitende/kookende kettels.

'Mobility assist dogs': Hierdie honde trek 'n persoon se rolstoel, dra artikels in 'n rugsak, tel voorwerpe op wat deur sy gestremde eienaar laat val is, maak deure oop en toe,

gaan haal items of haal items uit of op kaste en help ook sy hanteerder om aan en uit te trek.

'Walker dogs': Die honde ondersteun sy hanteerder om te balanseer of om as teenbalansering te dien. Hulle verrig ook soortgelyke take as bogenoemde mobiliteitsondersteunende honde.

'Seizure alert/response dogs': Honde word geleer om op 'n persoon se epileptiese toeval te reageer deur of by hom te bly of om hulp te gaan soek. Sommige honde word geleer om 'n knoppie op 'n konsol te druk wat dan outomaties 'n noodnemer skakel. Wanneer die hond 'n stem aan die ander kant hoor, begin hy te blaf. Sy eienaar reël vooraf met die nooddienste dat die stelsel deur sy hond geaktiveer sal word.

Psigiatrisse dienshonde: 'n Persoon met 'n geestesgebrek mag 'n hond benodig wat hom in staat stel om in die openbaar rond te beweeg, of mag dalk outisties wees en die hond help hom om te fokus. Hierdie honde word geleer om hulle metgesel nooit te verlaat nie.

'Combo dogs': Daar is ook honde wat opgelei word om persone met veelvuldige gestremdhede van hulp te wees.

Alle eer aan ons helpende vierbeenvriende! (Lees meer: www.servicedogssavelives.org; <http://sdogs.danawheels.net>; www.guidedogs.org.za; www.cci.org) ■

WORKING DOGS FOR PERSONS WITH DISABILITIES

The word HELP is a four legged word. Worldwide disabled persons make use of trained dogs to assist them in their daily lives. Unlike in other countries there is currently no legislation in South Africa to regulate service dogs. It is a disabled person's constitutional right that his service dog must be allowed to accompany his handlers to any place, including restaurants, schools, on trains, busses, airplanes, movie theatres, concerts, sport meetings, doctors' rooms and any other public and private place.

The Americans With Disabilities Act defines a service dog as any guide dog, signal dog, or other animal individually trained to do work or perform tasks for the benefit of an individual with a disability, including but not limited to guiding individuals with impaired vision, alerting individuals with impaired hearing to intruders or sounds, providing minimal protection or rescue work, pulling a wheelchair, or fetching dropped items.

A few categories of working dogs will be briefly considered:

Guide dogs: Probably the most familiar type is the guide dog that is trained to be the eyes of their owner and navigate him through traffic, up and down stairs and sidewalks while avoiding obstacles that could cause injury.

Hearing dogs: "Hearing" or "signal" dogs are specially trained to assist people with hearing impairment. They alert their owner to sounds, usually by approaching their owner and then by going back to the source of the sound. They are trained to react on noises such as doorbells, telephones, smoke alarms, crying babies, microwave bells and even kettles whistling.

Mobility assist dogs: These dogs pull a person's wheelchair, carry things in a backpack, pick up things his disabled owner drops, open and close doors, fetch things from or on top of cupboards and help their handlers to dress or undress.

Walker dogs: These dogs help handlers to walk by balancing or acting as a counter balance. They also perform many of the tasks that the above mentioned mobility assist dog does.

Seizure alert/response dogs: These dogs are trained to respond to a person's seizures and either stay with the person, or go get help. Some dogs are trained to hit a button on a console to automatically dial an emergency number. When the dog hears a voice on the other side he starts barking. His owner makes prior arrangements with the emergency services that the system will be activated by his dog.

Psychiatric service dogs: A person with a mental disability may need a dog to be able to go out in public or may be autistic and need the dog to focus. These dogs are trained never to leave their companions.

Combo dogs: There are also dogs who are trained to assist persons with multiple disabilities.

All honor to our four legged friends!

(Further reading: www.servicedogssavelives.org; <http://sdogs.danawheels.net>; www.guidedogs.org.za; www.cci.org) ■

Invitation to all graduates with disabilities

Since 1996, the employment situation of persons with disabilities are investigated. To help

micro and macro organisations, government and the corporate world with this process, VOC would like to provide such responsible citizens with a database of graduates with disabilities. It would be highly appreciated if people with disabilities could forward their CV's to voicesofchange.md@ufs.ac.za. We are focusing on both unemployed and employed persons with disabilities to contribute to the transformation for people with disabilities. ■



Geografie laat die aarde draai!
Geography makes the world go round!



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FUNNY STORIES WANTED

We are in the process of collecting true stories of funny moments experienced by people with disabilities. As we all know, often very strange or embarrassing things happen to us.

We want to appeal to Voices of Change readers who have a story to share to send us an e-mail. We need original stories that have never been published in any form before.

We also would need written permission that we may use and publish your story. People may stay anonymous if they would prefer not to have their names published. We are interested in the facts and the emotions of what happened and therefore people do not need to be concerned about any language mistakes in their mails. We shall appreciate any contributions. **VOC Team** ■



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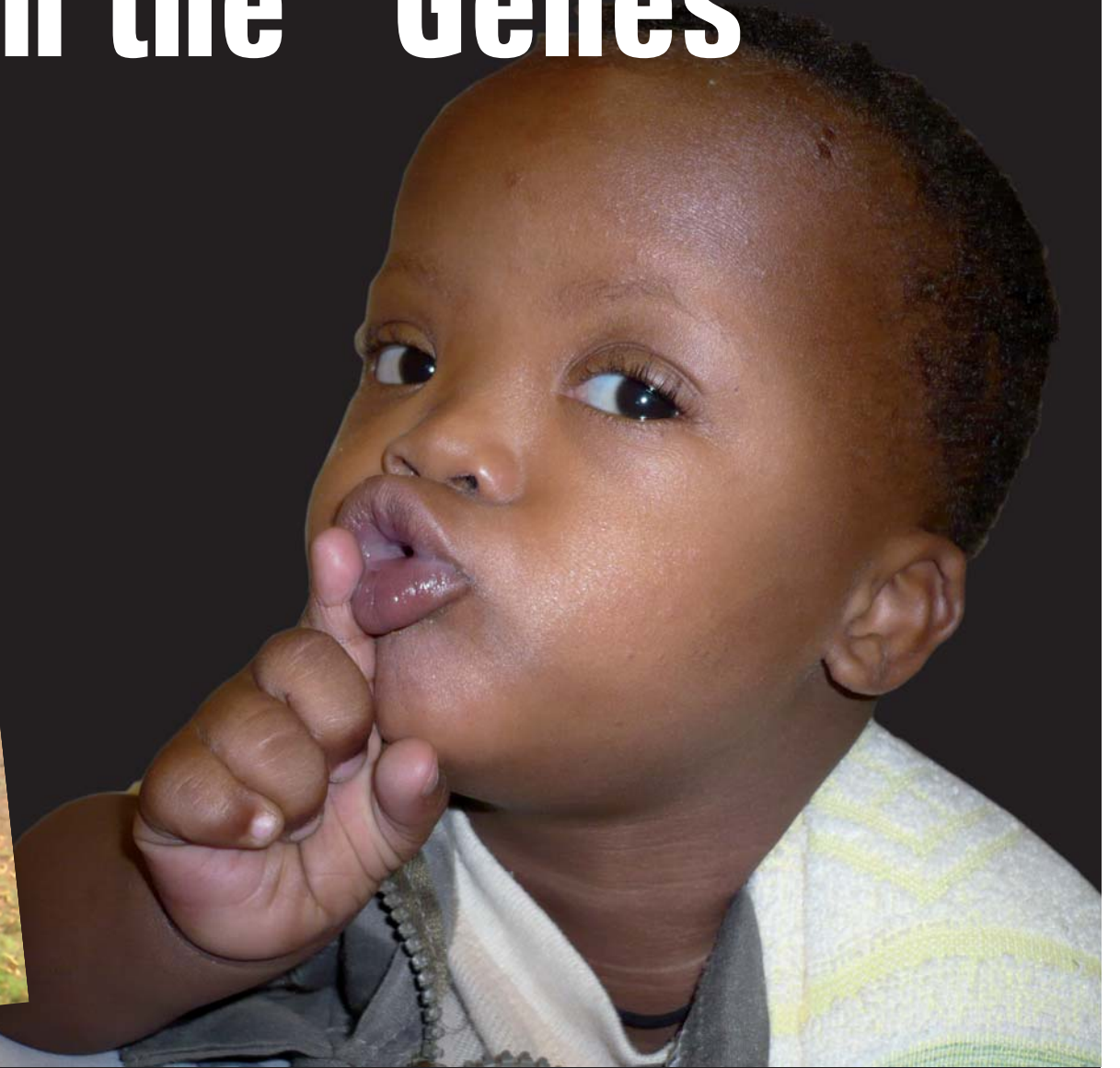
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Its all in the "Genes"



Dorothy Russel: Faculty of Health Sciences, UFS

Down Syndrome South Africa (DSSA) announces a new awareness campaign

Prof. André J. Claassen

Down Syndrome is a chromosomal disorder occurring in about 1 out of every 800 births.

Down Syndrome (DS) results when a person inherits all or part of an extra copy of chromosome 21.

There are many physical characteristics that are associated with DS. Not every individual has all the characteristics. Individuals with Down Syndrome are subject to a variety of medical conditions.

There is no cure for DS, however early intervention programs and integrated education can be extremely beneficial.

Children with DS are more like typically developing children than they are different. They look more like their families than they do one another, have a full complement of emotions and attitudes, are creative and imaginative in play and pranks. Children with DS benefit from the same care, attention, and inclusion in

community life that help every child grow. Love, attention, and stimulating chances to learn will do more than anything else to help children with DS reach their greatest potential.

Children with Down Syndrome can do what "typical" children can do, such as walk, talk, play, dress themselves, etc., however they generally do these things later than other children. Babies with DS benefit greatly from early intervention services beginning as soon after diagnosis as possible. Early intervention programs provide stimulating activities that often look like play but are meant to help the development of the child – communication, motor, mental, and social emotional skills are included in the programs.

Although children with Down Syndrome have a range of learning difficulties, physicians, educators, and parents now recognise that these children's achievements may be most influenced by what is expected of

them. These expectations are perhaps the most important factor in determining the educational and vocational potential of children with DS.

Raising any child fills a parent's life with delights and difficulties. There is great diversity in our world in terms of personality, learning styles, intelligence, appearance, compliance, humor, compassion, congeniality and attitude, and a child with DS may fit anywhere on the scale of diversity.

They are unique, responsive to their physical and social environments. Those who receive good medical care and are included in the activities of the community can be expected to adapt successfully – to attend school, make friends, find work, participate in decisions which affect them and make a positive contribution to society. People with Down Syndrome have the same emotions and needs as their peers.



To advertise in Voices of Change Contact Marianna Truter or Yolandri Terblanche

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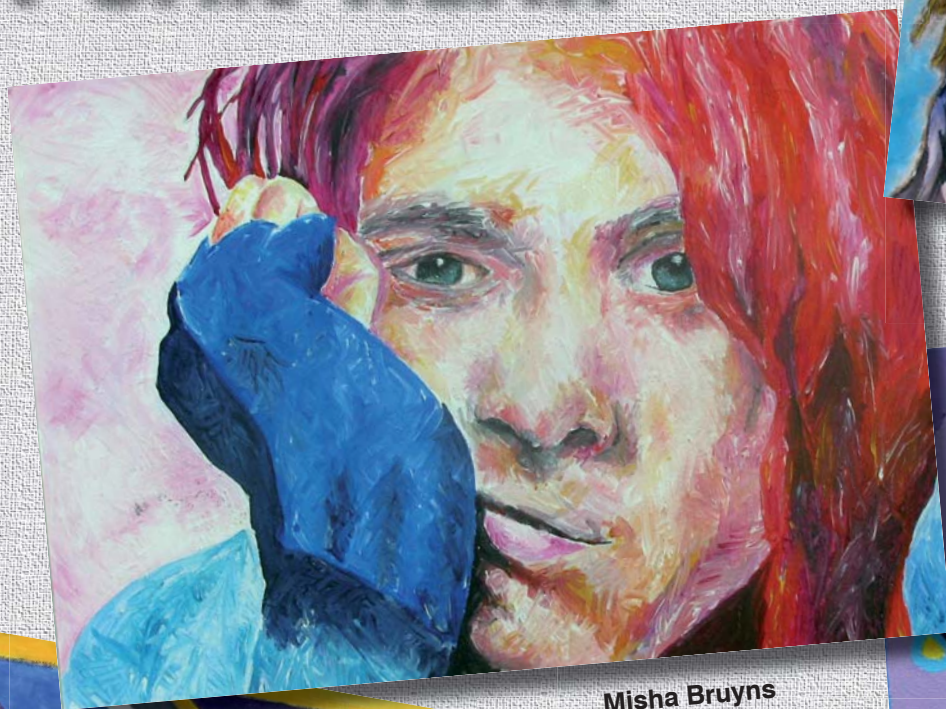
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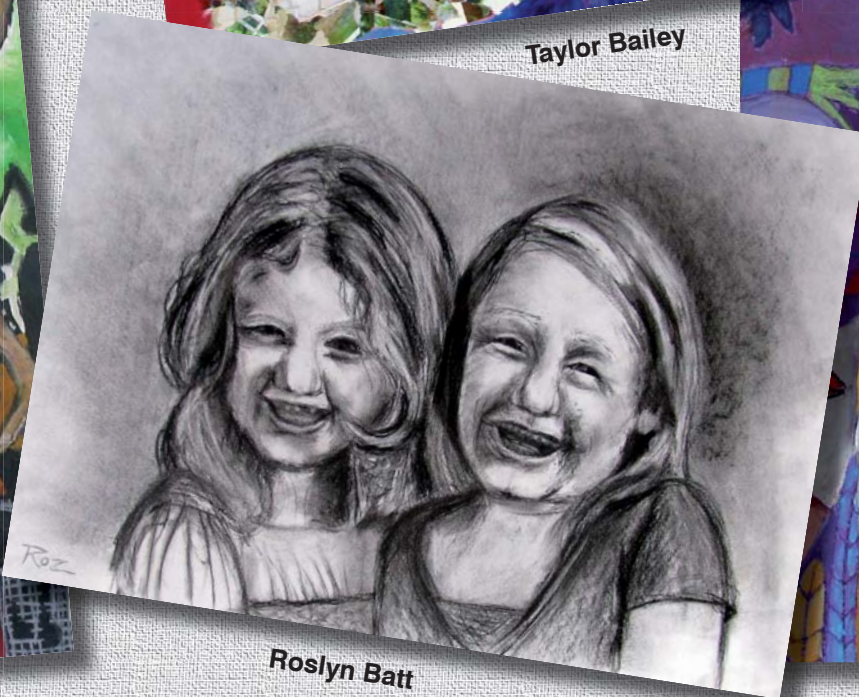
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Kgokelo ya bokahare ba tsebe (moropa wa tsebe)



Ngaka Iain Butler

Afrika Borwa

Lenaneo la Kgokelo ya Bokahare ba tsebe (BK) la semmuso Afrika Borwa le theilwe Stellenbosch ka 1986. Le ha ho le jwalo, pele ho mona, ho ne ho ntse ho ena le disebediswa tse mmalwa tse iketseditsweng "malapeng" Afrika Borwa. Jwale ho na le dibaka tse ding ntle le Stellenbosch, tsa dihlopha tse etsang Kgokelo ya Bokahare ba tsebe (moropa wa tsebe), Bloemfontein, Durban, East London, Johannesburg, Port Elizabeth le Pretoria. Dihlopha tsohle ke karolo ya "the South African Cochlear Implant Group (SACIG)" e fanang ka sebaka sa hore dihlopha di abelane tsebo.

Karolo e nkwang ke kgokelo ya bokahare ba tsebe (moropa wa tsebe)

Sesebediswa se hokelwang bokahareng ba tsebe se kgethehile haholo, e le ho ka fetola matla a

modumo temosi e hlabollang methapo-kutlo. Ke hona se qoba moropa wa tsebe o sa utlweng. Sena se bolela hore "modumo" o jarwang ke methapo-kutlo ho ya bokong, ha o tshwane le modumo o utluwang ke motho ya senang bothata ba kutlo. Ka hoo, motho ya hoketsweng bokahare ba tsebe o tshwanetse ho nka nako ya ho ithuta ho mamela ka sesebediswa sena se hoketsweng ka tsebeng. Ka lebaka lena, ho bohlokwa haholo hore mokudi e mong le e mong eo ho bonahalang hore o tshwanetse ho kenngwa sesebediswa sena; a kgothatswe, mme hape a fumane tshehetso e matla hore a tle a kgone ho ikamahanya le tshebetso e hlokalahalang.

Kgokelo ena ya bokahare ba tsebe e fapane le dithusa kutlo tsa pele. Medumo ena e ekeditsweng, e tshwanetseng ho feta ka kanale/ tsela ya tsebe le bohare ba tsebe ho ya ka hare-hare ho tsebe; e leng moo moropa wa tsebe o nkwang taolo teng jwaloka wa motho ya nang le kutlo e tlwaelehileng. Mona re lekanya hore kgokelo ya bokahare ba tsebe e ka sebediswa bakuding ba nang le kutlo e sallang, empa dithusa kutlo tsa pele ha di kgone ho thusa motho ya sa utlweng ho hang. Diqeto tse nkwang tsa hore sesebediswa se a hlokalhala, di ka etswa hantle ha ho rerisanwa le e mong wa dihlopha tsa ditsebi tsa kgokelo ya bokahare ba tsebe tse hohle mona lefatsheng.

Ditlathlitho tsa batho ba kgethelwang kgokelo ya bokahare ba tsebe.

E mong le e mong ya kgethelwang kgokelo ya bokahare ba tsebe o hloka ho hlahlojwa ke e mong wa sehlopha sa ditsebi tsa

kutlo. Sena ka mehla se bolela ho ikopanya le setsebi sa tsa Tsebe, Nko le Mmetso, hape le setsebi sa tsa Medumo le Puo. Ditsebi tse ding tseo ho ka kopanwang le tsona di kenyelletse Ngaka ya bana, Ngaka ya mahloko a kelello, Mosebeletsi wa setjhaba le Ngaka ya tsa lefutso. Ka mehla ho hlokalhala thuso ya mosebeletsi wa di "X-Rays" hore a nke ditshwantsho tsa bokahare ba ditsebe. Sena se bohlokwa tlathlitho ya sebopeliso sa bokahare ba tsebe le ya methapo-kutlo ho ka bona matshwao le sekgaoha sa bofokodi ba kutlo kapa tshenyeho e leng teng. Tsena di etswa boitokisetsoeng ba tsa tsheho.

Ka morao ho moo, diphihlelo le maikutlo a maloko ohle a sehlopha sa ditsebi a tla tshohlwa; taba ya pele, e le ho hlahloba mokgethwa/ mokudi, mme ya bobedi, ke ho hlophisa tsohle tse lebelletsweng ho yena le ho ba lelolo la hae. Mekgwa e sebediswang ya ho kgetha ba tshwanetseng ho fumantshwa kgokelo ya bokahare ba tsebe e thata haholo, moo e leng hore re ka lebella mahareng a diperesente tse 20 – 50 tsa bakudi bao ho ka thweng ha ba fumantshwa kgokelo ya bokahare ba tsebe. Hape pele ho ka hokelwa sesebediswa sa bokahare ba tsebe, bohloko ba bakgethwa/bakudi ba tla ba le nako ya ho fetiswa kwetlisong e matla ya puo le ya kutlo, ho sebediswa le dithusa-kutlo. Sena hase feela ho laola hore kgonahalo ya phumantsho ya dithusa-kutlo e tla lokela na, empa hape ke ho fa mokudi le sehlopha sa batshehetsi ba hae kutlwisiso e batsi ya tsohle tse amanang le pheko, e le hape ho fana ka pheko e potlakileng hang feela ka mora hore sesebediswa se kenngwe. ■

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