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**ACTION IN AUTISM'S PRESENTATION ON THE NATIONAL HEALTH
INSURANCE BILL TO THE PARLIAMENTARY PORTFOLIO COMMITTEE ON
HEALTH**

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Introduction and Objective

- The following presentation outlines Action in Autism's response and recommendations to the draft National Health Insurance Bill. In developing this response, Action in Autism held an engagement and dialogue session with members of its constituency on Saturday, 5 October 2019 from 2pm to 4.30pm.

What is Autism?

- Before outlining the submissions, it is necessary to explain what autism is, and what discrimination autistic persons face. Autism, or autism spectrum disorder (ASD) is a developmental, neurological and a social communication lifelong condition that impacts on all areas of communication and social interaction. People with autism struggle in social situations and have difficulties understanding neurotypical social norms and codes. Communication difficulties prevent persons with Autism from understanding much of another's body language. Since 93% of all communication is body language (facial, spacing, gestures, tones, emphasis, etc.) and 7% of all communication is what is said, people with Autism simply may not understand what is happening or how to respond. Autistic people typically have more intense, singular interests and feel their senses very strongly. They generally have difficulties with transitions and change in routines.

The DSM V

- According to the Diagnostic Statistical Manual 5th edition, authored by the American Psychiatric Association, there are now 3 levels of severity:- Level 3: Requiring very substantial support; Level 2: Requiring substantial support; and Level 1: Requiring support. Common co-occurring conditions with autism are Attention Deficit Disorder, Epilepsy/Seizure Disorder, Anxiety Disorders, Obsessive Compulsive Disorder, Mood disorders, i.e. Depression, Bipolar and sleeplessness.

It is a Communication Disability

- More than 50% of autistic people are nonspeaking, therefore providing an alternative means of communication is pivotal to ensure the rights of persons with autism to communicate and contribute to society. Alternative augmentative communication (AAC) encompasses the communication methods used to supplement or replace speech or writing for those with difficulties in the production or comprehension of spoken or written language. The most common and effective communication tool for non-speaking autistics is the Ipad with tailored software programmes that enable speech generation and communication.
- Autistic people were historically excluded from the public schooling system and were victims of institutionalised discrimination, stigmatisation and neglect. Some of the barriers they face in society are negative attitudes to and stereotyping of differences, inaccessible and unsafe built environments, and inadequately and inappropriately trained health care professionals and educators.

Background

- Action in Autism is a non-profit and disabled people's organisation based in Kwa-Zulu Natal that began lobbying the Department of Basic Education (KZN) in 2005 to make provision for learners with autism.
- Through its advocacy efforts a task team was set aside in 2006 with a budget of R1.5 million by MEC Ina Cronje to make provision for out of school learners with autism. This resulted in 12 schools in the 12 districts of KZN making provision for learners with autism.
- Action in Autism realised that this was inadequate and in 2011, the non-profit organisation partnered with the Department of Education (KZN) to host an Autism Indaba to accommodate out of school learners.
- Pivotal to this undertaking was ensuring that White Paper 6 on Inclusive Education, which detailed a strategy to include all learners with disability into the public schooling system, was adhered to.

Outcomes of the Autism Indaba (24 & 25 May and 14 June 2011)

- This three-day Autism Indaba was a truly multi-sectoral, consultative process – with all relevant stakeholders i.e. LSEN School Managers, District managers, CES officers, Circuit managers, representatives of Higher Education Institutions, FET colleges, Labour Unions, NGOs, parents and Department of Health and Department of Social Development represented.
- Each district had to return with a district action plan to present to delegates on the final day of the Indaba on 14 June 2011. A multi-sectoral evaluation and monitoring task team was also established to ensure implementation of the plan of action. **As an outcome of this process the Province, having refined and collated the action plans from all 12 districts, established an Autism Action Plan for Kwa-Zulu Natal.**
- The plan **enabled all 72 LSEN schools to receive annual tranches of R200 000 to support learners with autism and high support needs.** This process was aligned with White Paper 6 that outlines the establishment of a single, integrated learning system to accommodate the learning needs of all learners. Action in Autism has ensured that previously “specialised schools organised according to disability” now include all learners with autism and high support needs.
- We fought and advocated for the right of all learners to be accommodated within their district and their community and for the dissemination and development of skills and knowledge across the 12 districts of Kwa-Zulu Natal.

Outcomes of our Provincial Action Plan

- What this plan effectively did was to **decentralise specialised knowledge and expertise from the medical model of centralised specialised schools to ensure its development into all rural and outlying districts of KZN.**
- It advocated for and supported educator training across the 12 districts and brought persons with Autism into the ethos and fabric of LSEN schools.
- We continue to fight and lobby for the autism action operational plan to work from a social human rights paradigm, to ensure that learners with autism are afforded the same rights to education as all learners and as all learners with a disability, this in accordance with the UN Conventions on the Rights of Persons with Disability, The White Paper on the rights of persons with Disability, White Paper 6 on Inclusive Education and the Bill of Rights Section in the Constitution of South Africa.

The Action in Autism Centre

- Action in Autism has an established Early Learning Intervention, Adult Skills Development and Business Hub, an Assessment and Therapy Wing and a Resource Centre based at 105 Haig Road, Durban, 4051.
- The resource centre provides ongoing support to families and community members who support Autistic people. It is the only walk in resource centre in KwaZulu-Natal and as such provides pivotal service to a marginalised, vulnerable sector of society.

Action in Autism's ongoing projects:

1. A daily Early Intervention Centre, **the first one in the country** catering for learners with autism, which accommodates 32 full time learners aged between 2-6 years
2. A walk-in resource centre, **the only one in KwaZulu-Natal**, that provides support to the autistic community, counselling and support services to parents, information booklets, a database of health care professionals and a comprehensive list of schools and facilities that cater for learners with autism. In addition, Action in Autism also assists parents in accessing schooling and a social grant for their children
3. A Skills Transference and Business Centre for Autistic adults which accommodates 12 full time autistic adults. This will increase to 22 adults in 2020. A recently opened Assessment and Therapy Wing.
4. Free monthly parent, Asperger's and sibling support group meetings
5. Bi-annual Skills Transference Workshops, an ongoing programme to empower parents/educators/health care professionals with skills and strategies to support people with autism. This service is offered free of charge to under-resourced parents
6. Free, quarterly diagnostic and assessment clinics. Available only to those without private medical insurance
7. An annual Au'some Supermoms Pamper Day
8. Annual Mass Awareness and Year End Social events



**FEEDBACK FROM
CONSTITUENCY
ENGAGEMENT ON
THE NHI BILL ON
5 OCTOBER**

Contextual Experiences in the Public Health System


- Two parents spoke about their hospital experiences:

Lindiwe: spoke about her son who struggled with behaviour when he was young. She has epilepsy, and Lindiwe had an epileptic attack whilst at the outpatients at the hospital. The hospital threatened to call the police. They then took Lindiwe and her autistic son to a ward and told her that she can never come to the hospital on her own with her son.

A person with Autism gave written feedback on her stay at a psychiatric ward in a public hospital.

Mel was placed in the psychiatric ward for 7 days. She felt afraid to sleep at night. They were locked up in a communal cage and she became sick from the food. Patients with severe mental health illnesses were placed with those with autism. There was no understanding of those with autism. The male and female ablution facilities were shared. In the seven days she was there she saw the psychiatrist twice. She is still highly traumatised from the experience.

Germaine: mother of an autistic 8-year-old daughter Sarah. Sarah is often sick, and one day she started limping. Germaine waited to see if things would get worse; the school phoned for Germaine to fetch her. Sarah's leg was bandaged and later she was crying; Germaine had no idea what levels of pain her daughter was experiencing. She took Sarah to the hospital the next day. After X-rays, the medical staff said that there was nothing wrong with Sarah. After two days, both legs were affected, and she couldn't walk. They sent her home and said to come back when the medicine was finished. Germaine, small in stature, had to carry her 45kg child on her back. On their return to the hospital blood was taken, and again the hospital said that nothing was wrong with the child. She had been there from early in the morning, and she left at about nine that night. She had no money for transport. The hospital only gave Sarah Panado. Sarah was still in pain. She couldn't eat, talk, and stopped singing. Germaine thought her child would die. She was too afraid to go back to the hospital, as she didn't want to fight with them. With the intervention of Action in Autism, she then took Sarah to the KZN Children's Hospital and was seen by Paediatric Neurologist, Dr, V. Govender. Sarah was admitted to the hospital; the problem was neurological.



**FEEDBACK
FROM THREE
BREAKAWAY
GROUPS TO
PLENARY ON
THE CURRENT
PUBLIC HEALTH
SYSTEM**

Strengths & Challenges in the Current Public Health System

Strengths that exist in the current public health system

- Medication is free at public hospitals
- Some therapy, although infrequent is provided
- Autistic patients are given priority in some places
- More people have knowledge about autism
- There are facilities, even though this is not enough
- Some doctors prioritise treatment, and understand autism
- Acts of kindness towards our children is valued

Challenges that exist in the current public health system

- Exorbitant costs at private hospitals
- Too few experts in the field – diagnosis is then given too late
- Overmedication of psychiatric drugs
- Hospitals are noisy and sometimes smelly places – more awareness is needed around sensory differences of people with autism
- Our constituency endures long waiting periods
- The health sector is not trained on autism
- No understanding of disability, specifically neurodevelopmental disability amongst health professionals
- Patients see new doctors and interns at each visit – care and management is therefore difficult
- There is dysfunctional and, in some case, no medical equipment at some hospitals, i.e. MRI scanners not working.
- Management of medication is haphazard when one sees a different doctor at each consult
- Security guards are called in to hold patients down for e.g. blood tests

How can the system be strengthened to serve our community?

- Increase the numbers of specialist doctors in hospitals – many children are seen by general practitioners in public hospitals
- Train nurses and all auxiliary staff better
- There is an urgent need to train health care professionals across the value chain on autism spectrum disorders
- There is a strong need for a holistic approach to patient management from a multidisciplinary team
- There was also a strong lobby to provide multidisciplinary home team visits
- To eliminate queues for autistic people, the recommendation was that consults should be based on appointments, or to prioritise our constituency so they don't have to queue
- Healthcare workers should be more sensitised to girl children who can sometimes mask the symptoms of autism. The recommendation was that home visits could address this.
- There was a strong feeling in the house to lift the moratorium on all the therapy posts in hospitals and to employ more therapists like speech-language therapists with an augmentative alternative communication background, occupational therapists with a sensory integration background and psychologists who have an understanding of autism.
- Further development of therapists already in employment in the public health sector is required.
- There was a need to provide a service for the caregivers of autistic people who are admitted into hospital and have no one to care for their child
- There was also a call to provide transport to and from the hospital
- A recommendation was made to provide a dedicated waiting room set aside for autistic people – a calm, quiet space with few chaotic sightlines
- There was also a strong recommendation that mothers/main caregivers must be kept informed every step of the way in terms of hospital treatment and management
- Immunisation cards/ Road to Life Cards should include neuro developmental assessments
- There was a comment on the need for disability support officers to be employed in every hospital



RESPONSE AND FEEDBACK TO THE DRAFT NHI BILL

Response and feedback to the draft NHI bill

- Action in Autism is firmly supportive of an NHI Bill, an equitable healthcare system that serves all citizens in South Africa.
- Currently a lot of money is spent on healthcare, this amounts to almost 9% of the GDP but this is currently spent very badly. Neurodevelopmental conditions like Autism Spectrum Disorders and mental health has particularly suffered from poor medical treatment, mismanagement and poor resource and infrastructure.
- The Life Esidemeni Tragedy continues to haunt this sector of health care and is a sad indictment on the lack of service and care in the South African Public Health system. In a recent study of the State of health care and social adult care in England 2018/2019, which has its own national health insurance, it was found that “services for people with mental ill-health, or people with a learning disability or autism ...are finding it hard to get the support they need, when they need it.
- This might mean they end up in mental health services, but this could have been avoided if they had been helped sooner, for example, too many people with a learning disability or autism are in hospital, because there are not enough specialist services with the right staff where they live.” (October 2019, How good was health care and social care in England in 2018 and 2019).
- The autism community who have fundamentally a communication disability, those who are non-verbal and are unable to speak for themselves are particularly vulnerable and receive poor medical intervention and treatment.

Response and feedback to the draft NHI bill (cont.)

- Action in Autism's first concern is about early diagnosis of our people. The greatest challenge is the paucity of qualified diagnosticians and clinicians for autism spectrum disorders. Autism is a condition that needs to be diagnosed and managed, and families and community need to be supported and upskilled on best practice methods for life-long supports for people with autism. The NHI Bill must ensure the increased pool of qualified diagnosticians that are easily accessible, with an efficient referral system.
- Another huge problem that has been identified is the lack of a multi-disciplinary approach utilised in the public health system. Doctors don't have a broader understanding of the socio-economic or psychological context of the community from which a patient comes. Ultimately, we feel, it's about treating society.
- People who are socially integrated, economically active and psychologically stable should be the goal. Currently, most of our people come from poorly resourced, impoverished backgrounds, whose health care needs are not being met. In the current system their mental health is neglected and our people with autism are particularly vulnerable to neglect.
- Healthcare has failed to integrate into the social system. It is not talking to schools, political structures and broader society. Medical intervention is a small proportion of the needs of our community, the rest is optimising other aspects of life, and trying to create a better place for them in the world.

Response and feedback to the draft NHI bill (cont.)

- For the small percentage of people in our constituency that do have medical insurance, Autism Spectrum Disorder is not part of the prescribed minimum benefits of any scheme. Our community suffers because of this.
- Many services come out of day to day benefits, exhausting this meagre amount early in the year, with the main member having to cover the costs of most treatments.
- Therapies like speech-language therapy and occupational therapy are most often not covered by insurance and the medical and mental health of the community is exacerbated without these basic supports.



AMENDMENTS AND ADDITIONS TO THE NHI

Amendments and additions to the NHI

- We strongly and urgently request that Autism Spectrum Disorder is recognised as part of the basic package/ prescribed minimum benefits of the NHI.
- In terms of the constitution and the composition of the 11-member Board of the Fund (Chapter 4, Section 13, subsection (5) (b)), we strongly urge that expertise on mental health and neuro development management and care be included. This high-profile appointment will ensure that persons with disability and mental-ill health are prioritised. These mental health and neuro development experts must be cascaded down to all committees, i.e.
 1. **In the appointment of an expert technical committee for the sector (chapter 6, Section 24).**
 2. **The advisory committee, established by the Minister, chapter 7, Section 25, subsection (2) must include a person with expertise in disability, mental health and neuro developmental conditions and autism.**
 3. **Inclusion of an expert in the Health Care Benefits Pricing Committee (Chapter 7, Section 26, Subsection (2)) must likewise include a person with expertise that understands the disability sector and specifically the mental health sector.**
 4. **The Stakeholder Advisory Committee must include a disability expert (which must be a person with a disability) and be a person who has experience serving those with mental ill-health and developmental disabilities (Chapter 7, Section 27)**
 5. **Our community requires a one-stop, multi-disciplinary team approach with people who are knowledgeable, who can support our community from a health and lifestyle perspective. We therefore request that the primary health unit as indicated in Section 37, subsection 2 must include multi-disciplinary ward-based teams. Our caregivers and parents need to be strengthened and empowered on how to support their people with autism. We require an out of hospital, multidisciplinary team that helps with end to end management of our people with autism.**
 6. **The office of Health Products Procurement must include knowledge on essential medicine list and essential equipment list for autism (Section 38, subsection (4)). This should include basic communication devices and sensory equipment.**
 7. **The establishment of the Appeals Tribunal (Section 44, subsection (1)) should include a person with knowledge on alternative, augmentative communication systems, for people who cannot speak for themselves and for those with unreliable communication systems.**

Conclusion

- Autism Spectrum Disorders is a unique condition, the path for this extremely vulnerable community, needs to be optimised. When their social, psychological, health and educational needs are met it impacts on generations to come.
- As they grow, the needs of our community also change. This needs to be recognised across the health value chain. Currently this community is suffering immense health and psychological trauma.
- When the Australian health system, from the president down decided that mental health was a priority for the country, the entire country benefitted (*Crossroads: rethinking the Australian mental health system*, 10 March 2014).
- We want the same for our people. Our people need to be recognised as a vulnerable group that requires targeted support that is part of the primary minimum benefits of the National Health Insurance.