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VISION STATEMENT – SURVEILLANCE GROUP

IACP

Vision statement for the watch word: Surveillance

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Definition:

Developmental health surveillance in children with disability is the systematic and ongoing collection, analysis, and interpretation of indices of child health, growth, nutrition and development in order to identify, investigate and, where appropriate, correct deviations from predetermined norms. ⁽¹⁾

Child health surveillance programmes aim to prevent disease, detect physical and developmental abnormalities, and promote optimum health and development. Early intervention can change the life course for disadvantaged children. The emphasis now has shifted from detecting developmental problems to preventing them and, in recognition of this change, the term “child health surveillance programme” has given way to “child health promotion programme”.

The shift from surveillance to promotion requires a multidisciplinary team, contributing to health promotion as well as facilitating early identification and providing expert diagnostic and management services. Early intervention can change life trajectories; an integrated multidisciplinary approach involving health, education, and social services expertise is needed ⁽²⁾. The purpose of surveillance is to empower the decision makers to understand the situation and effectively manage the problems by providing timely and useful evidence ⁽³⁾

Any effective health intervention will reduce both direct costs and out-of-pocket expenditure. Child Health Screening and Early Intervention Services also aims at reducing the extent of disability, at improving the quality of life and enabling all persons to achieve their full potential ⁽⁴⁾.

The Vision

“Prevention of health problems and Promotion of health in children with Neurodevelopmental disorders”.

The Mission:

To identify early every child with Neurodevelopmental disorder and intervene early to prevent health problems and promote good quality of life

The **Objectives** of this group will be:

1. Development of a surveillance system for:
 - a) Early identification of Neurodevelopmental disorders at the National level.
 - b) Identification of complications like motor disorder, vision, hearing, hypothyroidism, intellectual disability in individual child, which can prompt interventions to prevent progress of health issues in already established Neurodevelopmental Disorders (NDD) cases.
 - c) By training and educating all Rehabilitation Professionals in Data collection and for better understanding the relevant aspects of NDD so as to provide meaningful information for policy making and for research

For this, Surveillance group will look at two aspects of surveillance:

1. Preventive surveillance:

The preventive surveillance aims at early identification of the following entities in high risk groups:

1. Vision problem
2. Autism,
3. Cerebral palsy,
4. Hearing
5. Intellectual disability
6. Learning disability

2. Surveillance for promoting health:

This aspect of surveillance aims at early identification of complications & health problem which interfere in Health Related Quality Of Life (HRQOL) in children with Neurodevelopmental disorders so that addressing these issues is likely to promote the quality of life.

This type of surveillance can include the following aspects:

1. Growth & nutrition including issues of feeding
2. Hip Surveillance
3. Bone health
4. Dental & Oral health
5. Convulsions
6. Psychological issues
7. Education, Schooling & vocational plan
8. Tertiary Musculoskeletal issues like joint & bony deformity, contractures and adaptive posture especially in transitional phase from adolescents to adults

The Strategy:

This watch word encompasses one of the most important activities in the field of neurodevelopmental disorders: monitoring. It deals with collection of enormous amount of data from all the aspects of the entity across country and consistently over time. The type of data that is sought needs to be precisely chosen so that it reflects important parameters indicative of important trends, changes and early markers of complications. The raw data has to be collected, processed and analyzed so that it reveals useful information. Next Factual analysis needs to be done and the gaps in the statistics need to be identified. Then the barriers and strengths of the outcome measures may be useful for policy making, monitoring progress and for research pertaining to neurodevelopmental disorders.

Involvement of other groups:

Purpose	Groups to Involve
Awareness for surveillance	Access, Empowerment, Leadership
Training manpower	Workforce, Leadership, Empowerment
Running on field data collection	Workforce, Leadership
Processing data and analysis	Research
Making surveillance relevant	Access, Research, Empowerment

In order to achieve this in a streamlined and time bound manner, the following would be the strategy:

Short term plan:

Plans	Strategies
Identifying parameters relevant to neurodevelopmental disorders in Indian scenario.	Setting up of a core committee (Sub groups)
A systematic search for proforma and restructuring them according to the needs of our country	Pertaining to their field of expertise, each Sub Specialist group will take up individual health issues to develop a consensus on a particular aspect of the collection.
Preparation of a proforma and its Translation	The group after refining the proforma will adopt an user friendly yet resourceful which is amenable to our country. Plan to employ translators and volunteers for translation into regional languages A pilot project will be envisaged and the Rehabilitation Professionals shall be trained as per the proforma. Data collection will then be done across selected regions
Running a pilot project	Data collection will proceed across selected regions
Analysis and Development of online/ app based data input	The technical group will analyze the need, feasibility and benefits of electronic mode of data collection and will execute the same if this form of data collection is comparable to the offline mode.

Long term plan:

Plans	Strategies
Training of personnel for collection of data	This will involve training a much bigger cohort of health workers involved in the care of children with neurodevelopmental disorders
Formation of a National database/ National Registry	The data base will be initiated at this stage to accommodate and store increasing volume of information

Analysis of the Data	The data that is collected will be undergo Factual analysis and outcome measures will be evaluated and Policy changes and Implementation by Government
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Time line:

The proposed timeline will be for two years for achieving short term goals. It will take another two years for the long term goals to be achieved

Steps for short term goals	Start time	End time
Identifying parameters relevant to neurodevelopmental disorders in Indian scenario: by core committee	0 month	3 months
A systematic search for proforma which are already there for assessment of such parameters and restructuring them according to the needs of our country	3 months	9 months
Making the proforma as user friendly,	3 months	9 months
Translation in regional languages	9 months	12 months
Training manpower in using the proforma and in data collection	12 months	15 months
Running a pilot project	15 months	21 months
Development of online/ app based data input	9 months	21 months
Analysis of the pilot project	21 months	24 months

Steps for long term goals	Start time	End time
Training of personnel for collection of data	24 months	30 months
Collecting the data	30 months	36 months
Formation of a national database: National Registry	36 months	42 months
Handing over the data to research group	42 months	46 months
Final steps, data end point and inference for the next phase	46 months	48 months

Details of the Surveillance Group Members:

SI No	NAMES AND QUALIFICATION	INSTITUTION	EMAIL ID	MOBILE	SUB GROUP
1	Dr Gayathri Devi C MD Paediatrics	BMC&RI	gay21164@gmail.com	9845929945	Growth and Nutritn gp
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10	Dr Sinil Das BSc BPT MHSc	VKM Special School, Kerala	sinildaspookkoti@gmail.com	9847214957	Disabilities in CP
11	Dr Dipa Dey (PT) BPT, MPT, Neuro (C?NDT), Fellow Ped PT	Institute of Human Reproduction, Guwahati	dipaphysio@gmail.com	7002737181	Disabilities in CP
12	Dr Nagarathna, MDS Pediatric Periodontics	GDC&RI, Bangalore	nagarathnagiri_1975@yahoo.co.in	9449631391	Oral Health gp

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Inputs from the Government bodies in aiding surveillance:

1. Health and Family Welfare Services Department
 - Sick New Born Unit (SNCU) Follow Up
 - Rashtriya Bala Suraksha Karyakram (RBSK)
 - District Early Intervention Centre (DEIC)
2. Education Department
 - Sarva Shikshan Abhiyan
3. Department of Social Justice and Empowerment.
 - Rights to People With Disability Act (RPWD Act)
4. Medical Education Department
 - Tertiary Level Care and Multidisciplinary management

References:

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3. David H Stone, “Terminology in community child health-an urgent need for consensus” Archives of Disease in Childhood 1990; 65: 817-821
4. Operational guidelines RBSK, Ministry of Health & Family Welfare Government of India
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