

RESEARCH- PRIORITIES & PROBLEMS IN CEREBRAL PALSY-AN IACP PERSPECTIVE

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INTERVENTIONS & PROPONENTS-CAN WE HAVE COMMON SCIENTIFIC ENDEAVOURS?

BELIEF BIGGER THAN EVIDENCE



IS THIS AN INDIAN SCENARIO?-NO!

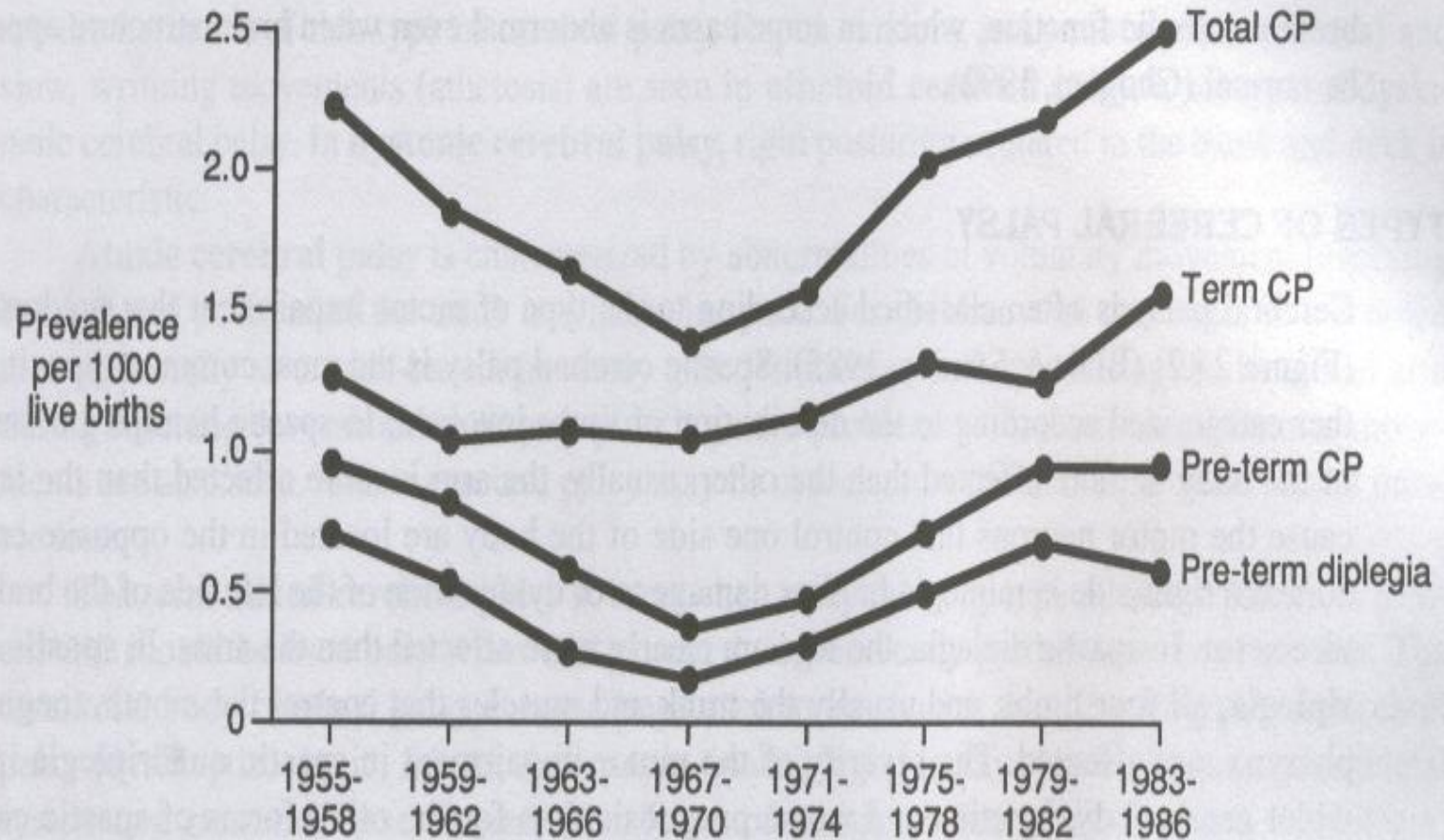


Figure 24.1. Prevalence of cerebral palsy 1955–1986. Over a 30-year period, there has not been a significant decrease in the occurrence of cerebral palsy (Hagberg et al., 1993).

- (Hagberg et al)

What is the picture in India in 2011- Raising relevant questions ?

- 1.Can small institutional Statistics give us the real picture of static or slightly increasing incidence in spite of accent on MCH services? What are our epidemiological trends?**
- 2.What are the predominant types of cerebral palsy in India & the status of their motor function? [F. Rice etal]**
- 3.Has neonatal care increased the overall disability load with inadequate neuro protection measures?**
- 4.Fullterm deliveries with cp, Increasing hemi plegic & dystonic syndromes or is it still the convenient preterm birth Bogie?**
- 5.Antenatal or peri natal or mixed causation?**
- 6.Fixing birth asphyxia in causation jigsaw puzzle?**
- 7.Are we missing the wood for the trees in Neuronal death due to Excito toxic cascade & prevention priorities? [Leslie L etal]**
- 8.Do we have enough evidence to support the many interventions in practice?**
- 9.Do we have standardized assessment protocols?**

DEFINING RESEARCH

- **CLINICAL PRACTICE IS APPLYING WHAT IS KNOWN TO WHAT IS NEEDED.**
- **RESEARCH IS THE EXPLORATION OF WHAT WE THINK WE KNOW OBJECTIVELY & TRYING TO KNOW WHAT WE REALLY NEED TO KNOW.**
[Martin Bax & Murray Goldstein]
- **BRIDGING & BALANCING THE TWO IS NOT ALWAYS EASY BUT IS THE NEED OF THE HOUR IN DISABILITY MEDICINE**
- **NEED INFORMATION IN INDIA FROM PREVALENCE TO INTERVENTION OUTCOMES-TO LIFE SPAN CARE.[Fiona Stanley,Himmelman, Dainius Puras]**
- **NEED EVIDENCE BASE FOR OPTIMAL CARE.**

WHO NEEDS EVIDENCE FOR WHAT?

- **DEVELOPMENTAL MEDICINE IS A COMPLEX MULTIDISCIPLINARY FIELD.**
- **BIGGER THE TEAM, PRIORITY NEEDS BECOME WIDER & DIVERSE. MANY IS NOT MERRY ALWAYS.**
- **WEANING FROM STAPLE DIET OF CURATIVE ILLUSIONS NEEDS GREATER RATIONALITY.**
- **CAN GOOD DOCTORS BE GOOD RESEARCHERS?**
- **NEED ANSWERS FOR OUR OWN QUESTIONS & THOSE OF PARENTS.[P.ROSENBAUM]**
- **WHO IS THE BENEFICIARY - STAKE HOLDER?-YOU, ME, FAMILY OR PESON WITH CP?**

FELT NEEDS VERSUS ADVANCES- AVOIDING TRAPS

- **COMPETING WITH WEST OR OUR OWN CULTURAL & REAL WORLD RELEVANT RESEARCH QUESTIONS & ANSWERS?**
- **BEYOND CURRICULUM VITAE CREDITS, PUBLICATIONS & INTERNATIONAL PAPER PRESENTATIONS-NO INDIVIDUAL GAINS.**
- **RESEARCH COMPLIMENTING IACP AIMS OF IMPROVING QOL OF PERSONS WITH CEREBRAL PALSY WITH LIFESPAN APPROACH& PREVENTION-
[Allan Colver etal, P.Baxter, Laura Tosi etal,CR Nuton]**
- **IACP NEEDS TO GROW BY VIRTUE OF WHAT WE DO & NOT BY WHAT WE TALK.**

TRANSLATIONAL RESEARCH – Where are Indian professionals?

- **T1-CONVERTING BASIC SCIENCE ADVANCES INTO TREATMENT MODALITIES.**
- **T2- CLINICAL TRIALS TO GAIN SOLID EVIDENCE.**
- **T3- CARRY OVER TO COMMUNITY HEALTH BENEFITS.**
- **GLOBAL TRENDS-T1& T2> T3.[P.Baxter]**
- **SHOULD WE DO SOME INTROSPECTION & SHIFT TO T3?**
- **``KNOWLEDGE TRANSLATION “the need to move new ideas in to the heads, hands & hearts of the people on the frontlines of childhood disability” [P.Rosenbaum]**
- **CLEAR CONSTRAINTS OF DEFINITIONS & SHARED LANGUAGE CONFUSIONS [J.Williams]**
- **CAN WE INFLUENCE MEDICAL CURRICULAR LAPSES & SPECIALTY CHOICES?. [J.Montovani]**

IACP PRIORITIES

[Dr.A.N.Johari]

- 1] EPIDEMIOLOGICAL TRENDS ACROSS THE COUNTRY FOR PREVENTION & ADVOCACY.**
- 2] PROFILE OF ATTITUDINAL BARRIERS TO EMPOWERMENT AT PROFESSIONAL, FAMILY SCHOOL & COMMUNITY LEVELS.**
- 3] NATION WIDE UNIFORM , VALID, RELIABLE ASESSMENT&TREATMENT PROTOCOLS & TERMINOLOGIES USED TO PROMOTE SHARED LANGUAGE & FRAMEWORK AS PER ICF GUIDELINES.**
- 4] CONVERT OUR VOLUME ASSETS TO LIFE SPAN MANAGEMENT MODALITIES**

THE PLENTY OF PROBLEMS – REAL WORLD IS NOT A LAB! .

- **COMPLEX NATURE&TRAJECTORY OF ND PROCESS WITH MULTIPLE VARIABLES**
- **CHANGING NEURAL SUBSTRATE**
- **GENETICS**
- **AGE BAND TRANSITION-CHILDHOOD IS A SOCIAL CONSTRUCT [Allen Colver]**
- **ENVIRONMENT-MICRO TO MACRO SYSTEMS**
- **PERSONAL & PARENTAL CHOICES**
- **EXPERIENCE- EXPERIENTIAL EXPERTS!**
- **VARIED HEALTH & EDUCATION SERVICE SYSTEMS ACROSS DIFFERENT STATES & NEED PERCEPTIONS [P.Baxter]**
- **LACK OF INFRA STRUCTURE & FINANCES**
- **ALL THE ABOVE OFTEN ARE BEYOND OUR CONTROL!!!**

WHOSE BABY IS DISABILITY- MEDICINE OR DEV. SCIENCES?

- **ALL PERVADING NEUROLOGICAL NIHILISM [N,DOIDGE]**
- **CURATIVE ILLUSIONS OR CARE SCARE?
POOR COUSIN OF HEALTH INITIATIVES& EDUCATION**
- **BIOLOGICAL , SOCIAL, RIGHTS BASED [RPDA]
OR FAMILY CENTERED MODEL DEBATES-
[P.Rosenbaum]**
- **ACUTE VERSUS CHRO.MED.HEADACHES?
LIMITED EXPERTISE, INTEREST & EXPOSURE**
- **DIAGNOSTIC TECHNOLOY AHEAD OF
MANAGEMENT OPTIONS—FIELD FOR ALL
ADVOCACIAL INTEVENTIONISTS!**
- **PAUCITY OF TRAINING MODULES & COHESIVE ACTION**

LOOKING BEYOND HORIZONS - CLINIC OR COMMUNITY ?

- **POOR RESEARCH EFFORTS & DESIGNS.**
- **PROBLEMS OF LIMITED NUMBERS& RECRUITMENT.**
- **DIFFICULTY IN DISEASE- DISABILITY MODEL PERCEPTIONS.**
- **ATTRITION RATES & NO MULTI CENTRE STUDIES.**
- **SAMPLE SIZE ISSUES & Randomised Control or Single Subject research Design ?[H.Graham &P.Rosenbaum].**
- **INADEQUATE TRAINING In R.METHODOLOGIES.**
- **PAUCITY OF LINK PROFESSIONALS & NAVIGATORS AMONG PARENTS, DOCTORS THERAPISTS, SCHOOLS , PSYCHOLOGISTS.**
- **LIMITED TREATMENT OPTIONS & NO EYE CATCHING MAGIC WAND IN SIGHT IN EVIDENCE BIASED WORLD.**
- **OBSESSION WITH NORMALISATION.**

INTERDISCIPLINARY RAPPORT-BRIDGING COMMONALITIES.



**MANY IS NOT MERRY ALWAYS!-
cohesive action & reality limitations.**

PATH AHEAD & FORWARD

- **THIS CME IS A BEGINNING TOWARDS THAT END.**
- **LET US INDULGE IN THE LUXURY OF PARADIGM SHIFT & LEARN BASICS OF RESEARCH TO FIND ANSWERS TO QUESTIONS WE PRACTICALLY ASK OURSELVES IN OUR DAY TO DAY PRACTICE & FIND ANSWERS FOR FAMILIES.**
- **BID ADIEU TO EMINENCE & OPINION BASED PRACTICE & WELCOME DEVELOPMENTAL SCIENCE IN ALL ITS RATIONAL BEST, GLORY, SPIRIT OF EXCELLENCE & ENQUIRY!**

NEW THINKING ABOUT WORK IN NEURODISABILITY- FIVE F'S

- **F1-FUNCTION.**
- **F2-FAMILY**
- **F3-FUTURE & FINANCE**
- **F4-FRIENDSHIP**
- **F5-FITNESS.-IN THE CONTEXT OF FUN**

[DR.GORTER]-

**CEREBRAL PALSY IS A GREAT TEACHER
FROM PHYSIOLOGY TO PHILOSOPHY,
EMBRYOLOGY TO ECONOMICS,HEALTH
SCIENCES TO HUMANITIES**

PUTTING DEVELOPMENT BACK TO DISABILITY! **-[P. ROSENBAUM]**

PT & OT

PEDIATRICS

ORTHOPEDICS

**SPEECH &
PSYCHIATRY,
PSYCHOLOGY**

**NEUROLOGY
ADULT .MED**

**SCHOOL &
FAMILY**

COMMUNITY

DEVELOPMENT AHEAD OF DISABILITY

IT'S UP TO YOU

One tree can start a forest
One flower can wake a dream
One bird can herald spring
One smile begins a friendship
One handclasp lifts a soul
One star can guide a ship at sea
One word can frame the goal
One sunbeam lights a room
One candle wipes out darkness
One laugh can conquer gloom
One touch can show you care
One step must start each journey
One life can make the difference

You see, **IT'S UP TO YOU**

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