

# **3x3... x4 Stories**

**MPC 1989 -2019**

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- ASC
- ARSC
- Michael Palin Centre
- ART
- SCIENCE
- CHARISMA
- 3 decades:
- 1989 - 1999
- 1999 - 2009
- 2009 - 2019
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# Rustin Teamwork Strategy

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- LENA RUSTIN, LCST
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- **Oxford Dysfluency Conference** **1984**
- World experts in the study of Fluency and Stuttering
- 
- **RUSTIN, L 1987.** The treatment of childhood dysfluency through active parental involvement. In L. Rustin, H. Purser, & D. Rowley (eds.) pp166-180. *Progress in the Treatment of Fluency Disorders* . London, Taylor & Francis.

**1984: 1st ODC**

**2020: 12<sup>th</sup> ODC**

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- **1989: Action for Stammering Children (ASC)**
- *Travers Reid & Lena Rustin* *funding*
  
- ”... a society...CYPWS have *same opportunities and quality of life* as their peers.”
  
- **MPC for Stammering children 1993**
- - *funded* by ARSC, Islington Primary Care Trust
  
- 1991: L. **Rustin** Editor 1991 *Parents, families, and the stuttering child.*  
San Diego: Singular.

**ASC**

**ARSC**

**MPC**

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# Causation Factors: *how does Stuttering emerge?*

- *NEUROLOGY*                      *GENETICS*                      *EPIGENIS*  
*ENVIRONMENTAL FACTORS* HOME                      *SPEECH & LANGUAGE*                      TEMPERAMENT

- *THE SEARCH FOR EVIDENCE*

*THERAPY* : WHAT WORKS?                      WHAT DOES NOT WORK?

- *PUBLIC ATTITUDES*                      *STEREOTYPE*                      *STIGMA*

- *FINDING SOLUTIONS*

- EDUCATION OF SPECIALISTS

**1989 – 2019**

**Improved insight, Evidence, Education**

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## 1994: 1st World Congress in Fluency Disorders (Munich)

- Alm, Bernstein Ratner, Boberg, Coopers, Conture, De Nil, Gregory, St Louis, Van Lieshout, Yaruss, +300 others
- Topics:      **NEUROLOGY**      *Motor speech*
- **ATTITUDES**      **LANGUAGE**      **EMOTIONS**
- **CLINICAL** management      **EFFECTIVENESS**

# Research in 1990s

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- **1995:** Proceedings 662 pages Vol 1
- (Ed by Starkweather and Peters)
  
- *Rustin, Kelman & Botterill* : Nondirective Interaction Therapy
- *Rustin, Spence & Cook*: Communication Skills w Adolescents
- Carindo, Rondini, & *Rustin*: Rustin Interaction Profile
  
- 4 more Books published before 1999

## **CLINICAL APPLICATION STUDIES**

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- *New data emerging*

- Prevalence

- < 1% c. **0.7%**

Incidence

c 5-8%

- Natural Recovery Estimates 1992-99

- Yairi et al 89%

Kloth et al 70%

- Language functioning above average for persistence

- Age; Gender; Family hx (65%)

- Predictive power of Linguistic skills?

- Genetics: family hx

# 1990s

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- 1999: IPATHA & POSHA-S K. St LOUIS
- ATTITUDES: STEREOTYPE AND STIGMA
- *Similar attitudes worldwide*
- c. 20,000 PEOPLE 44 COUNTRIES

**1999 -2019**

**20 Years**

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- **Biological basis for Stuttering**

## Genetics

- Genetic Studies: Linkage studies 2004-7

- CHROMOZONES                      9                      12                      13                      18

- GENE STUDIES to identify genes for stuttering :      DRAYNA et al 2010

- *WHAT IS BEING GENETICALLY INHERITED?*

- **Rustin, L., Cook, F., Botterill, W., 2001** *Stammering: A Practical Guide for Teachers and Other Professionals*. London: Taylor & Francis.

- Lena Rustin (d 2004)

**C21**

**1999-2009**

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# NEUROLOGY

# MOTOR SPEECH

Smith, A. Purdue 1989; 1990; 1996; 1999; 1997;

Watkins KE. et al, (2008), Brain, 131, 50 - 59

- “Our data support the conclusion
  - *that stuttering is a disorder related primarily to disruption in the cortical and subcortical neural systems supporting the selection, initiation and execution of motor sequences necessary for fluent speech production.”*
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- C 21 International Classification IDH
- **ICF** ICFDH functioning disability health
- Sociological approach to health and functioning
- Recognises role of environment in creation of disability
- **ACTIVITIES** and **PARTICIPATION**

**WHO 2001 2003**

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- **2003: WHO ICIDH to the ICF h**
- Focus away from Impairment, Disability Handicap
- to *Functioning and health*
  
- Sociological approach to health and functioning  
**ACTIVITIES PARTICIPATION**
  
- *major shift in defining disability*
- *Inspiration for new ASSESSMENT procedures*
- *Inspiration for new CLINICAL programmes*

**2003**

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- Epigenesis in stuttering: linking Nature & Nurture
- The Environment Influences Gene
- Temperament : emotional Reactivity (eg novelty) and Regulation (shifting attention away from stimuli)
- CWS low tolerance; low self-regulation
- Linguistics Language functioning
- 
- Studies in Neurology:
- Stuttering is a neurodevelopmental disorder whose primary symptoms are disfluencies, involuntary disruptions in the normal flow of speech.
- *Smith & Weber 2017*
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**2009 - 2019**

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2004: Alm *Basal Ganglia*

“...core dysfunction in stuttering ..... impaired ability of the basal ganglia to produce timing cues for the initiation of the next motor segment in speech.”

GENE STUDIES      Genes identified

- DRAYNA : Kang et al 2010      Pakistan      GNPTAB Chromosome 12
- Lan et al      2009
- Kraft, Cox et al      2012

**Single gene or polygenetic transmission?**

**How do they function ?**

**What is being transmitted?**

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- NEW DEFINITIONS OF STUTTERING
- Incorporating ‘neurogenic’ and ‘epigenesis’
- *EVIDENCE* OF EFFECTIVENESS STUDIES
- ‘Gold standard’ RCTs *Lidcombe* & *RESTART D & C* thy
- Clinical evidence: PCI SIS NT MINIkids.....
- Recovery studies: neurological and clinical evidence
- Millard et al. series of studies

**2009 - 2019**

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- A selection of publications:
- Biggart et al., 2007 A. Biggart,. Cook, J. Fry
- Kelman, E., Nicholas, **2008**. Practical Intervention ... Book: London T and F.
- Millard, Nicholas, Cook, Journal of S, L, H, Research • Vol. 51 • **2008**
- Millard, Edwards, & Cook, PCI Adding to the evidence. **2009**. IJSLP 11, 61–76.
- Millard, **2011**
- Onslow, Millard **2012** JFD
- Aumont-Boucand, Millard, & Packman, **2014**. Perspectives
- J. Fry, S. Millard, W. Botterill **2014**
- Kelman & Wheeler **2015** Cognitive Behaviour Therapy with children who stutter
- Millard et al., **2017**
- Millard, Zebrowski, Kelman. et al **2018**
- Ali Berquez and Elaine Kelman, **2018**
- Proceedings of the ODC, Sharib Millard & Brundage, **2018** **AJSLP**

## **Publications team MPC 2007-2018**

**Millard et al**

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## UNDERSTANDING CAUSATION:

Neurogenic-Motor speech

GENETICS

EPIGENISES

## UNDERSTANDING *Clinical*

AGE OF EVIDENCE

## UNDERSTANDING

*Public attitudes*

POSHA

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## • UNDERSTANDING SOLUTIONS

## • DEFINITIONS

THERAPY

Education: Specialists. ECSF

## • ICF (2003) .

Stutter **IMPACT**

**POSITIVE FOCUS ON THE PERSON**

# conslusions

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Questions

COMMENTS

***THANK YOU!***

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