We're all in it for the outcomes but which ones?

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*What do we mean by outcomes?

*A little history of outcomes in context of health

* Outcome measures in SLT

*Outcomes for people who stutter

*A possible way forward with outcomes for young children who stutter

Overview of presentation

effectiveness

Client goals

benefits in 'real world'

change

impact

Goal

Target

Effects

functional

Process

Outcomes

Various terms are used. Do they mean the same?

Is the need for outcomes as a means to improve interventions a new idea?

Florence Nightingale
1820-1910

Social reformer, statistician, and the founder of modern nursing

and remembered for her use of statistical measurement of nursing processes / practices to increase understanding of mortality rates and their causation

Outcomes and process: history

Codman, a Boston surgeon proposed his "end-results idea"

*....merely a common sense notion that every hospital should follow every patient it treats, long enough to determine whether or not the treatment has been successful, and then to inquire "if not, why not" with a view to preventing similar failures in the future [Codman, 1934, p. xii].Cited by Frattelli 1998, 9 (Measuring outcomes in Speech Language Pathology. Thieme New York)

His idea was not well received!

SLT outcomes are a more recent concern BUT have been considered for several decades e.g.

Andrews, G., Cutler, J. (1974) 'Stuttering Therapy - Relation between changes in symptom level and attitudes. Journal of Speech and Hearing Disorders, 39 [3], 312 - 319.

Helps, R. & Dalton, P. (1979) The Effectiveness of an Intensive Group Speech Therapy Programme for Adult Stammerers. British Journal of Disorders of Communication. 14 [2] 17-30.

Andrews, G., Guitar, B. & Howie, P. (1980) Meta-analysis of the effects of stuttering treatment. Journal of Speech and Hearing Disorders, 45 [3], 287 - 307.

Howie, P., Tanner, S. & Andrews, G, 1981, Short-term and long-term outcome in an intensive treatment program for adult stutterers. Journal of Speech and Hearing Disorders, 46 [1], 104 - 109.

Enderby, P. (1992) TOMS Outcome measures in speech therapy: impairment, disability, handicap, and distress. Health Trends, 20: 61–64.

Structure	Process	Outcome
Staff grades, costs of assessment tools, quality of accommodation	No. of interventions provided; no of patients seen	Changes in patients communication, wellbeing

Data to support quality assurance (Donabedian 1980)

Donabedian (1980) was one of the first to talk about structure process and outcome.
Donabedian, A. (1980) The Definition of Quality and Approaches to Its Management, vol 1:
Explorations in Quality Assessment and Monitoring.

*Intermediate outcomes:- from session to session is treatment benefitting client

*Instrumental outcomes activate the learning process- they trigger the ultimate outcome-

* Ultimate outcomes demonstrate the social or ecological validity of interventions

Rosen & Proctor (1981)

Rosen, A. and Proctor, E. K. (1981). Distinctions between treatment outcomes and their implications for treatment evaluation. Journal of Consulting and Clinical Psychology, 49 (3), 418-425.

*Frattelli (1998) wrote that the time was right for 'widespread application' of outcome measures.

*Identifies important features of outcomes:
  *Clinically derived
  *Functional
  *Administrative
  *Financial
  *Social
  *Client defined

Frattelli (1998) Measuring outcomes
in Sp-Lang Path

*improved use of existing function

*reduction of communication anxiety and avoidance

*improvement in interaction and effective social

  communication

*increased awareness of others about communication

*improved communication environment

*greater opportunities for communication

RCSLT CQ3 2006, 34

Parents	Children
Communication as the	*Fun and laughter
fundamental underpinning skill	*Friendships
Independence	*Feeling supported
Social inclusion	*Emotions
Other people's behaviour	*Communication
	*Other people's behaviour

Better Communication Research Programme

(Roulstone et al 2012)

User perspectives – valued outcomes

Roulstone,S., Coad, J., Ayre, A., Hambly, H. & Lindsay, G. (2012) The preferred outcomes of children with speech, language and communication needs and their parents. Department for Education- DFE-RR247-BCRP12 (https://www.gov.uk/government/publications/the-preferred-outcomes-of-children-with-speech-language-and-communication-needs-and-their-parents)11

- Wide variation in levels of 'outcomes'

Increased quality of life

1. Results of intervention

- Most written as 'goals' or 'targets'

Will use SVO structures in structured activities (70% of the time)

- Wide range and number of outcomes across and within themes (from 34 to 8)

Child Talk Findings so far...

Roulstone et al Child Talk study- currently being written-up. Check Bristol Speech & language Therapy Research website for future publications (http://www.speech-therapy.org.uk/)

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*Emotional wellbeing

*Social interaction

*Independence

*Participation and inclusion

*Academic achievement

But what is the evidence of change?

14 Outcome Domains identified including...

What outcomes should we use for:

*Children who stutter

*Young people and adults who stutter

* The Lidcombe Program treatment goal in Stage1 is *no stuttering* or almost no stuttering, and the goal of Stage2 is for no stuttering or almost *no stuttering to be sustained* for a long time. (

* A key goal is to improve the *family's confidence and skills* in managing their child's stammering. (Palin Parent-Child Interaction Therapy, http://www.stammeringcentre.org/early-intervention)

Stuttering Goals & Outcomes

Packman et al 2014), The Lidcombe Program Treatment guide can be downloaded from: sydney.edu.au/health-sciences/asrc/docs/lp_treatment_guide_0314.pdf)

*A primary goal of managing stuttering in school-age children and adolescents is to assist these clients to *speak more fluently in a wide range of settings,* with *confidence, independence, and self-reliance.* Under optimal learning conditions, children and adolescents should be able to *adopt effective and durable strategies in an efficient manner* that does *not* require an *excessive number of treatment sessions or prolonged dependence on the SLP.* (Nippold & Packman, 2012)

Stuttering Goals & Outcomes

Nippold, M. & Packman, A. (2012) Managing Stuttering Beyond the Preschool Years. Research Forum Prologue, Language, Speech, and Hearing Services in Schools, Vol. 43, 338–343

*The question of whether people who stutter want to speak fluently or feel better about communicating is totally irrelevant. When a person generates speech normally, the result is, of course, ***normally fluent speech and a normal ability to communicate***. Both these conditions need to be part of an evaluation of treatment outcomes. (Dahm, 2004)

* Presumably, if a school-age child could successfully control the stuttering, then the associated symptoms might diminish. (Nippold 2012)

Stuttering Goals & Outcomes

Research commentaries Commentary in partnerships between clinicians , researchers, and people who stutter in the evaluation of stuttering treatment outcomes by J. Scott Yaruss and Robert W. Quesal by Barbara Dahm. Stammering Research Vol 1, Issue1 Online journal BSA.

Nippold, M. (2012) Letter to the Editor: When a School-Age Child Stutters, Let's Focus on the Primary Problem. *Language, Speech & Hearing Services in Schools*. 43, 549–551.)

* …… evaluation of stuttering treatment outcomes can be enhanced through assessment of impact of stuttering on a speaker's quality of life.(Yaruss 2010)

*Three Realms of Measurement

Impairment: speech fluency

Reactions: affective, behavioral, cognitive responses

Disability: ability to perform tasks (functional outcome)
(Yaruss 1997)

Stuttering Goals & Outcomes

Yaruss, J.S. (2010). Assessing quality of life in stuttering treatment outcomes research. Journal of Fluency Disorders (Special issue: The Influence of Fluency Disorders on Quality of Life), 35, 190-202.
Yaruss, J.S. (1997) A Framework for Discussing Outcome Measures in Stuttering. ASHA SID4 Leadership ConferenceTucson, AZ (slide 22)

Results highlight the *potentially harmful influence that poor social support has on mood states for adults who stutter.* These findings have implications for treatment such as the necessity to address and integrate social support and social integration issues in the treatment process for adults who stutter. (Blumgart et al., In Press)

Stuttering Goals & Outcomes

Blumgart, E., Tran,Y. & Craig, A. (in Press) Social support and its association with negative affect in adults who stutter. Journal Fluency Disorders

*The differences in subjective wellbeing (SWB) .... point to the importance of wealth and relationships as buffers against challenging living conditions. (Cummins 2005)

*....there may be a relationship between SS (social support) and EI (emotional intelligence) which affects SWB (Gallagher, E. & Vella-Brodrick, D. 2005)

Subjective wellbeing (SWB) v.s QoL

Cummins, R. (2005) On the fifth anniversary of the Australian Unity Wellbeing Index: what have we learned about subjective wellbeing? In Cummins, R.A. (2010) Fluency disorders and life quality: Subjective wellbeing vs. health-related quality of life. Journal of Fluency Disorders, 35, 161–172. he suggests that AWB may be better measure than QoL-

Gallagher, E. & Vella-Brodrick, D. 2005 A presentation by Emma Gallagher, based on a

No shortage of potential areas to measure for outcomes and plenty of disagreement about what is important but we'll move on and consider who needs outcomes and then Benchmarking and why they're important

*A process that enables comparison of inputs, processes or outputs between providers

*Benchmarks are used as the [best] standard by which you measure your performance

*Analysis of **outcome data** can identify conditions under which programs do well and do poorly

*Need consistency between inputs, outputs, and outcomes. Outputs inconsistent = unreliable outcomes

Benchmarking

"Benchmarking is the practice of being humble enough to admit that someone else is better at something and wise enough to try and learn how to match and even surpass them at it."

(Basic of Benchmarking, Benchmarking Clearinghouse, p. 5).

Basics of Benchmarking 1993. Presented by the quality learning services division of the US Chamber of Commerce with Dr Carla O'Dell, American Productivity & Quality Centre (APQC) Item 302002. Downloaded from http://www.orau.gov/pbm/pbmhandbook/articles.pdf

Assurance for:

*parents and children - best possible, consistent standards of practice and outcomes (NHS, 2013)

*commissioners - services which provide best possible outcomes

*research - robust evidence base to evaluate effects and costs of different interventions

*the wider public - profession provides assured high standards evidence based, low in variability, best practice and predictable outcomes.

Who else needs outcomes / benchmarks & Why?

* 2 examples in this conference where benchmarks and information from case-note audits has enabled comparisons-
  * *The Internet Parent Training of the Lidcombe Program.* S. Van Eerdenbrugh.
  * *Treatment time with the Lidcombe Program: Benchmarks for bilingual children.* R. Shenker
* Benchmarking also useful when considering different versions of treatment e.g Webcam delivery of the Lidcombe Program for early stuttering: A Phase I clinical trial Sue O'Brian,

*Another way of looking at the range of outcomes needed to provide a funded service.

  *Tier 1. Health status achieved or retained functional level achieved, activities, and participation.

  *Tier 2. Process of recovery, nature of intervention, waiting times, time in treatment.

  *Tier 3. Sustainability of health status ongoing progress, functioning, participation and well-being

Three Tier model "Outcomes That Matter to Patients: A Hierarchy" Porter (2010)

Porter (2010) Principles of Value-Based Health Care Delivery, Ideas lab Downloaded from: www.hfma.org.uk/download.ashx?type=hfmatv-relateddocument...♪

Value-Based Health Care (Porter 2010)

Any relevance to stuttering?

-Prevention

-Early detection

-Right diagnosis

-Right treatment to the right patient -Early and timely treatment

-Treatment earlier in the causal chain of disease

-Rapid cycle time of diagnosis and treatment

-Less invasive treatment methods

-Fewer complications

-Fewer mistakes and repeats in treatment

-Faster recovery

-More complete recovery

-Less disability

-Fewer relapses or acute episodes-Slower disease progression

-Less need for long term care

-Less care induced illness

improvement,

Do we need another 40 years to get our outcomes sorted?

What can we do to ensure that:

*Future services for PWS will be provided by SLTs

*We provide the best possible interventions

*Understanding & knowledge continue to develop

*We meet the needs of our clients etc.
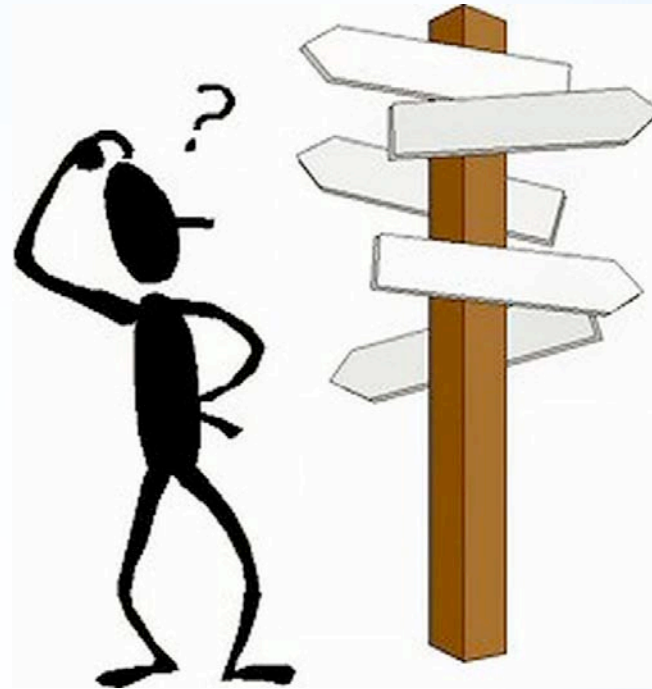
* ECSF and Stammering Support Center Leeds organized a mini symposium in Leeds (Sept 2013) for people who stammer, clinicians, and researchers.

*One group focussed on Early intervention and risk factors.

*From this we developed the idea of a minimum data set

Where next?

Report on Symposium can be downloaded on http://www.ecsf.eu/news-and-events/news-events/p/detail/final-report-mini-symposium-leeds.

*The idea:
  *A database would be developed where clinicians input case background & assessment data and intended action
  *Follow-up data would record process and outcomes at intervals (yet to be decided)

*This would get data out of filing cabinets and into a format where it can be used to: examine risks and outcomes, compare and contrast processes, examine cost:benefits etc

Minimum Data Set

Considerations:

*provided the data is collected routinely in clinic this is audit not research

*this is 'minimal' as a starting point- to encourage therapists to join up

*parent consent would not need to be obtained at initial interview- only before uploading data

*all data would be anonymised

*clinicians are free to collect other data

*it's not perfect but it's a start

Minimum Data Set

*No financial rewards for contributing to such an exciting
  venture

BUT

*it would great to be involved in such an innovative
  project

*HOW could it be done?

Minimum Data Set

*Who is HQIP - **Health Quality Improvement Partnership**

*HQIP works on various areas of quality improvement as well as our work on clinical audit. For example, HQIP also commissions and promotes best practice in clinical registers and databases.

HQIP-Healthcare Quality Improvement Partnership (http://hqip.org.uk/)

* HQIP has good links with those working on clinical audit in Europe, partly through the European Society for Quality in Healthcare (ESHQ), of which it is an associate member and is represented on the executive group; and through ISQUA, the International Society for Quality, in which HQIP staff have individual membership.

* In April 2012 HQIP hosted a major conference in partnership with ESQH on the development of registries in Europe

HQIP-Healthcare Quality Improvement Partnership
(http://hqip.org.uk/)

The following information from the interview with parents:

* Time since onset

* Type of onset (sudden/gradual)

* Male/female

* Family history of stammering and who in the family (relationship to child)

* A question to elicit description/comment about the child's personality or disposition re temperament e.g. *When something goes wrong how does s/he react? (e.g. tries again, get bit/very upset)*

Minimum Data Set: suggested data

In terms of the stammering components the following
 would be required:

* Co-morbid conditions
* Episodic nature?
* Developmental milestones
* Speech development, in particular, 'Was talking clear at
  the time stammering started?'
* Speech intelligibility

Minimum Data Set: suggested data

Environmental aspects:

* Child's reaction to stammer

* Parent's reaction to stammer

* How does the child respond to the parent's response to the stammer?

* Any awareness? How was this displayed?

* Parent rating scales (e.g Palin Parent Rating Scale see http://www.stammeringcentre.org for more information)

Minimum Data Set: suggested data

Follow-up Data

* Is your child still stammering?
* Nature of stammer?
* When did you last hear your child stammering?
* Has there been any treatment?
* A question to establish the level of concern

Minimum Data Set: suggested data

* Any and every possible clinician from a broad range of clinical settings
* Every child /parent who is referred for stuttering- initially children up to 6 years of age (?)
* Follow-up data collected until child 8 years of age
* Departmental commitment needed for collecting and submitting data over a long time-scale

Who could contribute and for how long?

A reminder of why we need to take new initiatives with outcomes

* "… maximizing value for patients [service users]: that is, achieving the best outcomes at the lowest cost." (p51)

* changes from within the professions because ultimately, value will be determined by how therapy is practiced

* Outcomes: evidenced, collected, and reported publicly in order that best practices are adopted and outcomes improved

'value-based' care (Porter & Lee, 2013)

Porter & Lee (2013) THE BIG IDEA THE STRATEGY THAT WILL FIX HEALTH CARE. Harvard Business Review Downloaded from hbr.org/2013/10/the-strategy-that-will-fix-health-care/ar/1‎

Finally:

*Please think about this idea - maybe you would like to contribute when we get it started or work on collecting data on older children/young adults or adults?

*Check the ECSF website for updates and contact details regarding this proposal

Thank-you!

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