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Outcomes from a short-term loan library: Challenges for clinical practice

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Challenges of assessing the impact of loaned equipment

The Communication, Learning and Technology (CLT) Service at Great Ormond Street Hospital, London, offers specialist advice to children (80-100 per year) with communication needs. Trial of equipment forms part of the pathway of care which aims to establish successful communication systems for children. **Assessment findings**^[1] determine a "short-list" of trial equipment, which is loaned to children for 6-12 weeks. **Evaluation** of the impact of equipment then forms the basis of recommendations for purchase and support.

Appraising the outcomes of these loans has proven challenging: measures relevant to identifying the success of communication systems are much debated. Valuable measures in the long-term based on increased participation, quality of life, or academic achievement may be of little use as indicators of potential benefit during a short-term trial. Evaluation of the impact of *loaned* equipment needs assessment of potential value since the full impact of the equipment may not be apparent.

2002 -> 2006

During a nationally funded project (Communication Aids Project), specialist centres were encouraged to collect simple data relating to the impact of any equipment purchased. Local teams determined three communication targets and our analysis showed focus on a spread of communicative competencies^[2]. Results showed that 63% of targets were not achieved^[3]. Analysis suggested a number of themes underlying these apparently poor

- inappropriate provision (matching) of equipment
- demands of the equipment too high for the child's abilities
- inappropriate targets set
- equipment only available for limited trial through distributors
- lack of support and training at a local level

Our response and change of practice

- establishment of loan library (2006) to offer longer, evaluated trials of equipment
- recommendations for increased and focused assessment of children's abilities prior to loan
- increased access (telephone and email) to specialist knowledge and expertise giving local teams additional support
- decision to continue the use of targets, perhaps with more focus and specificity, to help determine loan outcomes

2007 -> 2009

We elected to trial Goal Attainment Scaling (GAS) in the light of the system's reported value to multidisciplinary team working and the relevance to a wide range of equipment/abilities. GAS goals use a 5-point scale, with the highest and lowest scores linked to most and less likely outcomes. GAS had previously been trialled for use in the field of AAC^[4]. Goals were set jointly by the child, their family, their local team and our service^[6].

We were able to discuss the role of **SMART** (**S**pecific, **M**easurable, **A**chievable, **R**elevant, **T**ime-bound) goals in valid evaluation. Analysis of "incoming" goals from local teams, and our own early attempts suggested that many of the goals were not robust across these SMART parameters.

There are a number of acknowledged difficulties with the GAS methodology: however, for us, the major issue was that negotiating, "SMARTening" and documenting goals, each with a five-point scale, was too time-consuming for clinical practice.

Our response and change of practice

- Working closely with local teams to discuss SMART targets was reported to be of great benefit
- Goals set were still very much within the communicative competencies framework^[2]
- We needed to develop measures of service effectiveness, and to look at other aspects of efficacy^[4]
- We acknowledged the influence of the International Classification of Functioning, Health and Disability (ICF)^[5] to help consider the role of the child's abilities, the environmental facilitators and barriers, and the equipment characteristics

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2010 ->

Clinical review by all stakeholders

Three goals are drawn from a child's existing communication targets. The outcome of these goals forms the basis for discussion at the end of a loan. We gather information as follows:

■ In-Child Factors

Is enough known about the child's cognitive profile, language needs, visual and attention abilities, motor skills and social communication needs? Should some more assessment be undertaken?

■ Team Involvement

Identify all stakeholders, and document their opinions and concerns, as well as their attitude to existing and / or proposed communication systems. Have all stakeholders (including funders) had an opportunity to comment on the trial and its outcome? Have records been kept of the trial and of instances where the system has been effective / ineffective?

Equipment Factors

Was the equipment reliable and did it work as expected? Was it well-supported and was adequate training sought and provided? Did any stakeholders find it more or less difficult to operate or personalise?

Opinions and Preferences

For all stakeholders, we would ask "What has been the impact of adding this equipment to the child's current communication system?" and "What do you think might be the impact in the future; say, in a year from now?"

■ Participation

The "ultimate" goal of a communication system is to increase the ability of children to join in with family, school and community life. Evidence of this within the trial is discussed and suggestions are made for how this might be evaluated in the future.

Service Effectiveness

Outcomes now include information about purchase of equipment, collected via telephone interview 6 months after recommendations have been made by our team. For 2010-12 84% of 31 recommendations were implemented locally:

	Purchased	Not Purchased
Recommended	18	2
Not Recommended	3	8

Case Study – The Challenges of Short-Term Outcome Measurement

Avigail has a diagnosis of Prader-Willi Syndrome: she has language comprehension within the normal range, but reduced speech intelligibility and some difficulties with fine motor movements. Avigail was referred to our service for identification of communication equipment to support her social development At our initial assessment we made the following recommendations:

- Speech was likely to continue to be Avigail's primary channel of communication
- An increased emphasis on signing would support her speech
- Although not of obvious and immediate relevance, the role of any assistive technology should continue to be considered

Questions about technology to support her speech were again raised as Avigail entered school. We therefore arranged a 12 week loan of a touchscreen PC with specialist communication software. Following this loan, we met with all parties involved outcomes were recorded as follows:

- Speech continued to be Avigail's primary channel of communication and, in consequence, the device had not been used to support her speech and signing
- The local team had found the device useful in lessons for Avigail increase her rate of written work
- It was felt that a further loan focusing on this role might be helpful, although some stakeholders expressed concern that using the equipment might impact on the development of hand-writing
- A further 12 week trial of a device with focused literacy support software was organised and training was arranged for school and therapy staff

The second loan was evaluated by all stakeholders and the following findings were noted:

- School and therapy staff supported the device enthusiastically, and regular additions of vocabulary had been made
- The device had been integrated into all aspects of Avigail's daily activities
- The device was described as "a necessary tool to support her learning [...] allowing her to speed up her work, increase production and aid fluency"

For The Future

- Return to GAS for individual effectiveness outcome measurement?
- Further exploration of Schlosser's model of efficacy, to support measurement across effectiveness, efficiency and effects^[6]
- Further exploration into recording opinions and preferences of developmentally young children (below 2 years)

 Stakeholders willingn
- of developmentally young children (below 2 years)
 Consideration of the findings of the ISAAC-UK (Communication Matters) Outcome Measures for AAC committee

Challenges highlighted

- Trials can have unexpected outcomes: devices may have an impact on spoken or written communication, on play, attention, environmental control...[8]
- Stakeholders willingness to trial equipment flexibly can only be valuable: there is no bad outcome from a loan!
- How should we measure the support made available during the period of trial?
 The enthusiasm, knowledge and attitudes of stakeholders are hard to quantify and compare.

