

COST ESSEA

Meeting minutes WG4, Tours 29 & 30/5/2012

Present: Helen McConaghie, Magali Batty, Anett Kaale, Marlene Lauritsen, Mikael Heimann, Bernadette Rogé, Iris Oosterling, Erica Salomone, Michele Noterdaeme, Judith Sinzig, Petra Warreyn (minutes), Frédérique Bonnet-Brilhault (30/5), Antonio Narzisi (30/5), and Filippo Muratori (30/5)

Introduction

Several people joined the workshop since the Padua meeting. We started with a short introduction of everyone and a resume of the Padua meeting.

Scientific presentations + group discussion

6 scientific presentation were held, followed by a group discussion.

1. Iris Oosterling: Possibilities for sharing data on early intervention (reciprocity studies)

Iris presented a possibility for data sharing including 4 reciprocity studies. So far there are no ethical boundaries to do this meta-analysis.

The main research question is: What is the influence of parent training on the development in language and social communication skills after one year of intervention. A possible second research question (maybe to be addressed in a second study including more studies with other intervention content) is: Which predictive characteristics of toddlers and preschool children with autism could be identified regarding development in language and social communication skills?

Outcome measures are language (MCDI, ADOS A1) and social-communication skills (ADOS revised algorithm & MCDI gestures). Possible predictors are age, gender, DQ, language, social communication, repetitive and stereotyped behaviour, ADOS severity score.

Timeline: May/June 12; design paper framework & database format, Sept/Nov 12: gathering of data, Dec12/Jan13: analyses, Feb/March 13 writing paper, April 13: revise draft(s) based on comments co-authors, May 13: submit paper to JADD. Possible STSM from Helen to Iris to work together on that. Detailed planning will be worked out in discussion with Helen and Sarah Wigham (during the first week of July).

2. Erica Salomone: Mapping services and interventions – European parent survey.

Erica has piloted the survey. Parents (well educated) found it difficult to know what treatment was delivered. The survey will now include an information page first where parents can see all the treatment options that will be presented, and also are shown the option for 'other' treatments. Info

will no longer be asked about the last 6 months, but about a typical week. The survey will be launched in autumn.

Comments: is there no back translation needed? Text is easy and short to translate. Would take a lot of time and resources. But would show differences between countries. Difficulties in translations are reflecting differences in settings. Suggestion: ask translators to mark (or have a list) the things that had to be adapted to the national situation in order to make it clear for the parents.

Concerning recruitment: from September onwards, website online for one month (parent organizations contacted in advance). Erica will draft a kind of cover letter, can be adapted to national situation, to be sent to the parent organizations. Given practical issues, October / November would be a better period. Another question: do we need separate ethical consent? There is ethical approval from UK (see last mail). Several people have asked whether national data will be available for national publications (feedback to parents is motivating). Survey will also end with debriefing page.

3. Judith Sinzig and Luise Poustka: Mapping services and interventions – European survey through ESSEA representatives.

We had a group discussion about the goal of this mapping: do we want an expert opinion, or do we want to know what is offered in a country (20 experts, 20 opinions?). Consensus: It is important to get an idea of the differences between countries. We may need to show to some countries (governments) that some things should be provided above others. There will be 4 levels of questions: what people usually get, what we would recommend, what is funded by the state, and what kind of formal services there are.

Another question that arose was: How many people should we ask? We want to know what is typically available versus not typically available. Maybe we should ask each delegate: are there large differences within your countries? Are there several people needed? A draft will be available at the beginning of July (for feedback by (the end of?) August). Possibly STSM from Germany to Erica.

In terms of future intervention studies, this survey should result in a questionnaire for care as usual that is similar in all countries over Europe (and resembling the parent questionnaire).

4. Petra Warreyn and Bernadette Roge: Comparison of schemes for coding parent-child interaction in play.

Petra presented an overview of the similarities and differences between the different coding schemes. Bernadette reported on a coding exercise done by two student, comparing two different coding schemes.

Points discussed by the group: 1) what are the differences between coding schemes focussing on (detailed) frequency counts and schemes using more qualitative rating scales in terms of sensitivity to change, ease to obtain inter-rater reliability, capturing the essence of the interaction, ... and 2)

would it be useful (and feasible) to focus on sequences of behaviour / bidirectional interaction patterns rather than frequency counts?

Other points:

- Mikael Heimann also used Bloom's procedure, which is more focused on language development (including synchrony of comments)
- We should also have a look at the rating scales used by Mahoney et al in intervention research (responsiveness, ...)
- Erica was trained by Ssally Rogers' group (ESDM): focus of coding scheme was on learning opportunities, based on free play sessions. Took into account chains of behaviours and how parent was contingent. Erica can ask to share the coding scheme.
- We want to improve interaction: this is between two persons. Looking at parent / child / together: together is the most important aspect.
- Possibility to create a new coding grid, integrating the best elements of the existing ones?
- There may not be one ideal coding scheme, but the scheme is depending on: population (typical / atypical), focus (language / behaviour), specific questions asked, practical aspects (e.g. possibility to film or code as you watch), ...
- STSM's: Antonio is going to Jonathan Green for 2 weeks, one of Michele's students is also going to Jonathan Green: possibility to go at the same data, to allow for comparisons?
- Training school on this topic: see below

5. Helen McConachie: Measurement of parent adherence.

Helen is working on an update of a worldwide review parent mediated intervention. In 2003 there were 2 RCT papers. Now there are 18 papers, but only 5 report some information on how they measures parent adherence. Two studies asked parents to report on the number of hours trained, two used video scoring, one used parent report (6 items on adherence and competence).

Question: how do we think we could collect information from parents on implementation? Can we make recommendations? Different things suit different approaches. Iris asked the professional how well they thought parents were doing. In the ESDM (Bernadette), a professional can evaluate fidelity, for themselves, other professionals or parents. There are precise criteria. Erica will send the English criteria to Helen.

In any case, not enough studies are reporting parent adherence to write a research paper on it. It would be useful to write an editorial commentary instead of research paper, highlighting it as an issue.

6. Iris Oosterling: ADI-toddler replication

Iris proposed a possible joint project, initiated by herself and Annelies De Bildt. The aim would be to study the usefulness and psychometric properties of the new diagnostic ADI algorithms for toddlers, as proposed by Kim & Lord (2012).

Actions: Iris will send around the requirements to join this study, anyone who has a sufficient amount of reliable data can join.

Training school 2013:

We do not expect to be able to train people in one preferred or 'ideal' coding scheme by then, but do think that a summer school/training school on parent(adult)-child interaction measures would be useful. To be held in Manchester, led by Jonathan Green. Possible items that could be covered:

- Present what is existing (external speakers)
- Introductions in different schemes (workshops)
- Discuss important dimensions and the relation between research questions and useful methods

We plan to further prepare the training school in a face-to-face meeting in autumn, where we can perhaps invite experts on the field. If possible within the budget, we may propose a second training school in 2014, actually containing a training in one or more coding schemes.

Other points discussed

- We think it would be useful to have a second face to face meeting this year in autumn, possibly partly joined with WG3.
- Possible topics for new STSM round later this year:
 - o Possibility to ask for STSM on exploring shared data between reciprocity studies? One person to visit several sites? Or make lists each on how databases are set up (eg full items or subscale scores)? (Iris & Helen will discuss this further)
 - o Judith would like to send someone to Erica in Nov/Dec, by the time the survey data are available
 - o Mikael would like to send someone to Uppsala during the training school
 - o Helen would like to send someone to Joaquin to discuss computer-based/games interventions and related outcome measures. There is also a team in France developing these games.

- Not enough people from WG4 are planning to go to the Autism Europe meeting in the fall of 2013, so we decided not to attach a WG4 face to face meeting to the conference. We may consider to attach a meeting to the 25th Annual Meeting of the EACD, in October 2013 (Helen is in the scientific committee, and there will probably be an early intervention symposium on the meeting).
- Judith will send around an invitation to the WG4 members to present an early intervention symposium at the Scientific Meeting for Autism Spectrum Conditions in Bonn, February 2013.
- There may also be a possibility to present on the next ARAPI meeting in Le Croisy.
- Additions to the website. Helen will update the WG4 list and send to Tony & Herbert, then if people are listed on the website they have to send their information to Louise.
- Publications: for example, editorials describing ESSEA. With permission of Tony and Herbert re the table on COST website (also Filippo, Bernadette, Petra and Sigridur re unpublished studies) Helen proposes an editorial for Child: care, health and development. Nb. Important to use form of words agreed about COST.
- Mapping of ongoing studies is harder to achieve (than published studies). Email was sent to all COST members in February 2012, making clear we want to be put in touch with other groups doing current controlled early intervention studies in the country. Two new studies notified.
- We discussed the possibility to collect information by research site, i.e. on level of readiness to do multi-site intervention studies in future, resources and barriers. This will be an action point in 2014, as close as possible to the 8th framework calls.
- On our next phone conference on June 27th, we will discuss the possible mapping of ethical principles relevant to intervention studies.