

## **COST Meeting Bilbao; 30/4/13 & 1/5/13**

### **Meeting minutes WG4**

Present: Frédérique Bonnet-Brilhault; Bernadette Rogé, Michèle Noterdaeme, Judith Sinzig, Anett Kaale, Erica Salomone, Karen Ashwood, Iris Oosterling, Antonio Narzisi, Tony Charman, Jonathan Green, Mikael Heimann, Christine Freitag, Luise Poustka, Helen McConachie, Petra Warreyn

#### **Parent-child interaction coding as an outcome measure**

Separate lines of work were presented by:

Petra Warreyn (ESR): Frequency coding versus rating scales in a within-family mother-child interaction study

Jonathan Green: Coding parent-child interaction with the DCMA

Michèle Noterdaeme: Analysis of dyadic communication interaction in asd: evaluation of a standardized parent based intervention

Anett Kaale (ESR): Adult-child interaction in autism: interaction measure and some results

Helen McConachie and Magdalena Glod: Coding parent-child interaction as an outcome measure of interaction.

Mikael Heimann: Parent-child interaction, deferred imitation and pretend play in speaking and non-speaking children with autism

These presentations were followed by a group discussion. Discussion points were:

- potential value in coding behaviour (coding blind, generalisation measure, ...) as outcome measure
- rating scales versus frequency/proportion counts – capturing different elements (eg. rating is quicker, may capture quality of parent responsiveness better than frequency counts – which are in turn a better representation of child behavior?)
- what is the focus/theory of the intervention? This then affects the content of the coding scheme
- differentiating coding of ‘parent fidelity’ to the intervention techniques versus coding quality of naturalistic interaction
- definition of terms varies between coding schemes (synchrony / joint engagement)
- proximal to the intervention (did parents take on what they were taught)
- is it a mediator or an outcome measure? how predictive is it in the long term?
- influence of child language on coding
- need to be coding parent, child AND dyad
- changing PCI cannot be the goal of the intervention, but rather long term outcome (school, QOL, ...). it is a proximal outcome. if only the proximal outcome is affected, perhaps the intervention is not useful.

- can we at least agree on a standard set of toys, instruction to parents, length of time, ...??

Future actions:

- Helen and Petra to write a discussion paper on this topic (2014)
- Will be important to take into account in a possible future multi-center study

### **“Legacy”: How will we continue after the end of this action?**

Several preliminary ideas were explored and discussed:

- adopt same outcome measures & combine samples? (parent and child predictors of change?)
- or short, focused interventions for early core difficulties (e.g., joint attention for 6 weeks) in several centres simultaneously?
- head to head comparison of different interventions (e.g. EIBI vs reciprocity; joint engagement intervention in nursery/by parent/both)?
- what is feasible in different sites? e.g. psycho-education in groups would be more feasible to implement than ESDM in a nursery. (But evidence of effect in literature not very strong, perhaps greater for lower functioning children – Carter et al 2011, McConachie et al 2005)
- we will need to find a compromise between scientific evidence and feasibility. Perhaps should look at model of implementation science, ie processes and barriers to getting a service developed, or numbers of hours increased, in different settings.

### **Treatment as usual in different countries**

Two presentations:

Judith Sinzig: European survey on treatment as usual – professionals view (TAU-P)

Erica Salomone (ESR): Survey of Service Provision for Young Children with ASD Across Europe.

An individual discussion per country will follow. Erica and co-authors will try to write the first paper on the TAU survey as soon as possible (in total 3 papers planned).

Judith will start working on a paper concerning the professional survey. Needs first to complete missing data, and include some information about country guidelines.

Concerning the parent survey: Erica will suggest a general feedback to the parents ASAP.

Representatives per country can adapt this for their individual situation.

Emily Jones from EU-AIMS will discuss whether a staff member could apply for a STSM to work on converting the TaU parent survey to a questionnaire.

## Outcome measures

Will be a topic of the next teleconference (dates to be agreed).

- will come partly out of the mapping (table) → Petra will send this round again and will perform a new literature search
- Helen will check for any new European papers identified in the MeASURE project search of intervention studies.
- lead will be taken by Anett, Mikael, Iris (her PhD student), Christine & Frédérique) → preliminary call with Helen and Petra will be planned
- relation with EU-AIMS (Jan)? (outcomes for medication trials)
- Bernadette will make presentation about 'burden of care' at next face to face meeting (ie as relevant to choice of outcome measures for family members)

## Joint meeting WG3

1) A possible joint topic, cultural aspects in screening and intervention, was introduced.

Presentations by:

Frederique Bonnet-Brilhault: issues in adaptation of a Cancer Locus of Control Scale, including translation and cultural issues.

Rafal Kawa: Cultural aspects in the delay of diagnosis (and interventions)

Several possible next steps were explored. This is also a possibility to propose an STSM to gather together data from different countries on differences between immigrant and host populations on delay in diagnosis.

2) Second joint topic, the replication of the ADI-R toddler algorithm, was presented by Iris (see attached slides). Group discussion about possible causes for lower sensitivity in comparison with the original study.

Dates for telephone meetings to be circulated.

Next face to face meeting: 9<sup>th</sup> October 2013, Newcastle upon Tyne, UK (information on booking travel to follow).