



(Enhancing the Scientific Study of Early Autism)

COST Action BM1004

COST WG4 7/8 April 2014

Academiegebouw, Domplein 29, 3512 JE Utrecht

Meeting minutes

Monday 7th

Present: Christine Freitag, Helen McConachie, Tony Charman, Michele Noterdaeme, Antonio Narzisi, Sue Fletcher-Watson, Marlene Lauritsen, Anett Kaale, Erica Salomone, Mikael Heimann, Selda Ozdemir, Iris Oosterling, Judith Sinzig, Petra Warreyn

13.30 – 15.00

Interventions:

Discussion on what focus of early intervention would be interesting and feasible for several sites. Since many of the group are interested in reciprocal interventions, we will focus on that. We want something that is reasonably time limited, in order to limit practical difficulties and confounding factors, and maximize retention of participants. Short iterations are much more flexible and have more chance of being available to different countries and communities. Group discussion on contents and what children and families need.

Several short presentations of the Content of short focused early interventions (content; how delivered; duration and intensity): Mikael, Anett, Petra, Iris (child-focused); Michèle, Luise & Judith (parent psycho-education).

Mikael: A comparison between two treatments for young children with autism. EIBI (similar to ESDM) compared to intensive imitation (starting point = Jacqueline Nadel). 4h/week, preschool setting, child leads versus 15h/week, preschool+home, therapist leads. Newly diagnosed children. Compared first 12 weeks of intervention. Effect sizes a bit better for EIBI, but very similar in intensive imitation. (Personal experience Mikael: seems to work best for nonverbal children; might work as kind of jump start for social motivation).

Anett: Joint attention intervention in preschools. Based on Kasari's JASPER intervention (2006, has developed since then, with some add-ons from the 2010 mother-child intervention), adapted to Norwegian preschool setting. Goal is to increase JE and JA. In mainstream preschools (with extra person for the child with ASD), by preschool teachers, 2 20-minute sessions a day for 8 weeks. Trained counsellors (3 day WS) in turn trained teachers (+ weekly supervision). 5 min at the table (ABA-based but joyful and based on child's choices, e.g., prompted to show and point), 15 minutes of floor play (facilitate spontaneous occurrence of JA). Gains in JA (with teacher) and JE (with mother), evidence for generalization and maintenance of results at follow-up, no effects on language.

Petra: therapist-led intervention targeted on imitation and joint attention. 24 one-on-one sessions of each 30-45 minutes, twice a week. Combination of developmental and naturalistic behavioural techniques.

Iris: used PRT as parent training. 4 aspects: Motivation for social interaction; motivation for communication, multiple cues (attend to multiple aspects, e.g., little red car), self-management (having idea of and managing own behaviour). For young children motivation to enjoy social interaction in combination with initiating social interaction is important. Following the lead of the child, depending on level of functioning. 12-15 sessions with parents. First demonstrating with the child, then explaining techniques to parents, parents take over & get coaching. About 45 minutes per session.

Michèle: T-ASK. Parent-based, immediate after diagnosis. 9 sessions over 3 months, 3 parts: 1: learn about autism; 2: make them confident that they can interact with the child (e.g., joint interactive play, detect communication signals and respond to them) + one individual session to adapt techniques to the child; 3: more joint interactive play, reduce verbal behaviour towards the child, adapted to individual children. Goal of the program: Provide parents with useful techniques for daily life, in play situations. Age 3-5. No waiting period.

Intermediate discussion about need for parent training in addition to therapist-led program: people agree that it is in any case useful (may not always be necessary, depending on the situation and child)

Christine: Integration of PRT, imitation-joint attention, ... in parent training. Parents receive this immediately after diagnosis. 8 sessions, parents of max 5 children. Flexibility in sessions (e.g., toilet training just for interested parents). Fixed sessions: psycho-education, seeing the positive things (difficult immediately after diagnosis), own resources and support, behavioural models (get an idea of how to change behaviour in the child), own examples of behaviour (change), communication, information on interventions and schools, focus on different problem behaviour. First sessions once a week, last sessions a bit later. One session = 2 hours. Duration is about 14 weeks. Content of the sessions is somewhat dependent on level of the children (trying to create quite homogeneous groups). Therapists are psychologists schooled in behavioural therapy

Judith: parent programme shortly after diagnosis; impetus was fact that waiting list for autism center is about 1 year: filling this gap: 8 sessions of psycho-education, talk about diagnosis, symptoms, etiology, neuropsychology in daily life, intervention, possibilities for schools, welfare system, parents' rights, course and prognosis. Next 8 sessions with therapeutic intervention (behaviour therapy, reinforcement,

positive interactions). Currently being evaluated for high functioning children and adolescents, can be adapted to younger children. Given by two psychologist trained in behaviour therapy.

Discussion of what type of intervention has good theoretical grounding, good pilot data, could be delivered in several sites in Europe.

Conclusion: there seem to be two approaches in these presentations: one about the human right to get psycho-education and information, one about stimulating specific abilities in the children. These approaches are not mutually exclusive. Possibilities will depend on national systems and habits, e.g., in Norway, almost all parents already receive psycho-education so that would be difficult to randomize.

Possibility to plan one day face to face meeting to generate design ideas for future trial?

16.00 – 17.30

Report from STSM:

Petra Warreyn preparation for a trial of joint attention/imitation training along with extra practice delivered by tablet (Edinburgh, Ghent)

Report of activities and conclusions of the past week + plans for last days of STSM. Discussion about way that therapist and app would complement. Having real-world interaction opportunities built into the app. Different aspects: matching community situations, making app appealing, matching it with intervention, building in-app data collection, developing outcome measures (proximal and more distal).

Mapping services:

Judith Sinzig findings from survey of professionals

Discussion of the findings and how to present them in an appropriate way. One conclusion is that the health and social welfare system are paying for several alternative and non-evidence-based treatments. It would be worthwhile to look at website that rates evidence level for every intervention type (e.g. Research Autism based in UK). Based on this we could structure the data in categories (possibly advantageous, definitely not, ...). Who is paying for an intervention is perhaps not relevant, if it is paid for. Contrast health care, social & educational against private. Also relate whether the availability of alternative treatments is dependent on the (absence of) availability of evidence based ones.

Erica Salomone: parent survey of services.

Final draft of first paper to be circulated very soon. Discussion of possible journal. This is not only relevant to Europe, but to everyone. American studies would be published in international journals as well. Agreed to aim for JADD first.

Question about data sharing agreement. Question about feedback to parents.

How to evaluate how much treatment is a basic minimum. Perhaps the people who said that there are national guidelines can send the number of hours to Erica, if it is explicit in the guideline. Perhaps data driven, lowest 10% is low number of hours of therapy?

Initial goal of creating a questionnaire to be used in intervention studies to document hours of TAU: how to achieve this and how to spread this? EU-AIMS made a start with this, but it should also be disseminated. Action point for Helen & Petra to see if this version can be disseminated.

Tuesday 8th

Present: Helen, Sue, Marlene, Anett, Mikael, Erica, Antonio, Michele, Petra, Selda

9.00 – 10.30

Self-evaluation of WG

Besides getting to know each other.

Guidelines on early intervention: not feasible. Research in this field is not at the stage to say what children should receive. We know that there are children getting dangerous or ineffective 'alternative' treatments. Also: in Europe there are more generic therapies available and used than 'branded' therapies. Surveys started to build to an evidence base about what is currently received.

Also had good discussions about how to evaluate interventions (depending on content of the intervention). + this will result in a paper.

List of papers: 7 papers in process or planned; tried to look at essential building blocks about how to strengthen research design. Others things to do? Book? (no). Special issue? (too late?).

Had various discussions about ways to go forward. Now we know what common interests are.

Report from STSM:

Sue Fletcher-Watson parent child interaction outcome measures

Anders (Norway), Romuald (France), Helen, Sue. Sharing knowledge about 2 coding schemes: BOSCC and joint engagement coding scheme. Consider practical applicability for coding scheme to use with EDT (Romuald). Prepare a paper directly comparing coding schemes (Anders, Sue, Helen, Anett): recode pre-post intervention measures from Anett (currently JE) with BOSCC, see if effect is comparable (both on a group and individual level), and if BOSCC score is independent of language and IQ.

Group discussion about BOSCC. At the moment it can be used for research purposes, but this has to be negotiated with WPS.

Outcome measures:

Anett Kaale tools used in published studies (2002-2013) in Europe, and apparent sensitivity.

Background: lack of consistency in use of outcome measures: no comparison possible across studies.

Important issues in selecting outcome measures: related to treatment targets, suitable for heterogeneous ASD group and sensitive to changes, feasible for the study design. Difference between comprehensive and targeted treatments (outcome measures for the former have to be broader than the latter). Also difference between RCT's (more controlled measures as well) and controlled studies (more clinical measures). This has to do with the rules of RCT's.

Discussion points: subscales versus total scales: makes a difference

Unit of analysis? concept, instrument, or even way of scoring the instrument. Inconsistency across trials is worth demonstrating/illustrating, e.g., in one example like language. Why do people choose to use these scores/scales/...?

We cannot recommend a standard set for every study, but perhaps we can suggest a core set of instruments that makes sense. In addition suggest that people can choose raw scores, standard scores, ... depending on the sample's level, but e.g., at least have raw scores so it can be pooled and compared.

Adding sensitivity to change to the presentation makes sense, without having to discuss all psychometric properties.