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GAMUT – Griegakademiets senter for musikkterapiforskning
Uni Health, GAMUT – The Grieg Academy Music Therapy Research Centre

TIME-A NEWSLETTER No. 2/2012
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Dear collaborators,

Much has developed since the first newsletter that was sent about half a year ago. The kick-off meeting that will mark the official start of the project is also approaching fast. In this newsletter we have some news from the central office and some contributions from collaborators.

1.) Milestones in preparing the study

- From Molloy College, we have heard that they are the second site (after Austria) to have received IRB (ethics) approval. Congratulations to John and his team!
- The study protocol has been published as a journal article in BMC Pediatrics. The final version can be found here: http://dx.doi.org/10.1186/1471-2431-12-2 and replaces all earlier versions. Thanks to Monika and Ulla for their contribution to this article!
- Later changes may still occur in the form of protocol amendments. One amendment has already been made and is available on the project website (see below).
- The project website has been established: http://helse.uni.no/timea – thanks to Karin and Rune for that! It contains general information about the project but will also be a growing repository for publications, newsletters, protocol amendments, FAQs, and other material. Contributions from all of you are welcome and should be sent to Karin and Christian.
- Applications for funding have been sent by collaborators in Korea and USA.
- Collaboration agreements have been signed for almost all countries.
- A PhD position has been advertised in Bergen and we have started to evaluate applications.
- The kick-off meeting will take place from June 4-6, including an open day ("International Study Day", see the project website) on June 5. We are very happy that collaborators from almost all countries will be coming and look very much forward to welcoming you in Bergen.

2.) Discussion on the use of the ADOS

Review of Gotham, Pickles & Lord (2009) by Grace and Margot:
There has been debate amongst researchers about the appropriateness of the ADOS as an outcome measure for ASD interventions. The ADOS has four modules to choose from depending on the person's developmental level. It is scored with a 4-point likert scale which allows severity to be assessed in some way; however the scoring was designed for diagnosis. Summed algorithmic scores are compared to thresholds which result in a classification of either "autism", "autism spectrum disorder" or "nonspectrum".
While designed as a diagnostic tool, the ADOS has been used as an outcome research in research.

One reason for this is that the ADOS assesses the core features of autism and gives an indication of severity. ADOS scores are also more independent of IQ scores than other diagnostic tools such as the CARS, GARS and ABC. This is important because the ADOS does not measure ASD severity in terms of language delay, cognitive functioning and behavioural issues. Clearly these aspects have an impact on an individual's overall functioning and participation in community; but they are not the core features of the autism spectrum.

Another measure that successfully measures social impairment independent of IQ is the SRS. The SRS is a parent/teacher report measure, which can be seen as a limitation or a strength depending on your view on these matters.

Before 2007, it was difficult to use the ADOS as a measure of change in severity over time. This difficulty was due to the fact that as a person gains language skills, they move up to a higher ADOS module, making the raw scores non-comparable across time. In 2007, the original algorithms were revised to improve comparability of scores and therefore longitudinal comparisons.

While this was an improvement, a normalisation of severity of autism from the ADOS scoring was still missing. Gotham, Pickles & Lord (2009) aimed to "generate standard scores that would approximate a severity metric for the construct of 'autism spectrum' as it is measured on the ADOS." (p.694). A severity metric ranging from 1 – 10 (with 10 being the most severe) based on ADOS raw totals was then calibrated. This offered a method of quantifying autism severity in a way that is relatively independent of age and verbal IQ. The metric had more uniform distributions compared to raw totals, with the authors concluding that these scores are therefore more suitable to longitudinal comparisons. If using the metric, researchers should understand that this does not measure functional impairment, but provides only "a marker of severity of autism symptoms relative to age and language level." (p. 703). However, this metric is yet to be fully tested for reliability and validity. Using it could be appropriate and potentially contribute to the field in general.

As with all measures, there are limitations. Gotham, Pickles & Lord (2009) reported that 20% of ASD assessments received the highest score of 10, creating a ceiling effect. Additionally, those who moved from module 2 to module 3 in subsequent testing may have had an inflated severity score. Future directions may include calibrating the Social Affect (SA) and Restricted Repetitive Behaviour (RRB) domains separately to measure severity within these symptom domains.

Comment from Christian:

Thank you. I am sure this discussion will be with us for some time. Methods for scoring the ADOS are still developing while we are embarking on this project and that is of course a challenge. As you have noted, the ADOS discriminates relatively well from other non-specific developmental delays and has also been used as an outcome. I am not sure the "calibrated severity scores" described by Gotham et al. are a step forward in our context, because (in addition to the ceiling effect mentioned) they involve rounding and therefore a *loss* in precision and sensitivity. They do make the modules more comparable, but our protocol already specifies that the same module should be used in all measurements of the same child. Another issue related to the ADOS is training. I would like to suggest establishing a working group on the use of the ADOS (as part of the scientific advisory board to be established) to deal with such issues.

3.) Discussion on IQ testing

An update on the use of the K-ABC in Australia from Grace:
The K-ABC is actually not widely used in Australia. This is because it is considered culturally specific to USA and takes more than 45 to complete. Not many children with ASD are able to do the tasks, which make it an unpleasant clinical experience.
The KBIT2 (Kaufman Brief Intelligence Test) has been used in some local research projects to good effect. It is quick to use, and does not need a psychologist to administer. This measure is not as detailed as the K-ABC, but is considered much more feasible.
Other more common intelligence tests in Australia are the Wechsler Scales:

- WPPSI – Wechsler Preschool and Primary Scale of Intelligence (children aged 2;6 – 7;3). All children in Victoria Australia have this test just before they start school, so around 5 to 6 years of age.

- WISC –Wechsler Intelligence Scale for Children (children aged 6 – 16)

On reading the published study protocol, I notice that the assessor can informally assess the child's cognitive functioning if the child will not/cannot comply with the testing situation. While for most low functioning, non-verbal children you could safely infer "moderate to profound mental retardation" (similar to if the child was unable to participate in any intelligence test), distinguishing between mild and moderate may be quite difficult as the way ASD children present is not necessarily representative of their cognitive functioning. I look forward to continuing the discussion on intelligence testing/assessing.

Comment from Christian:
Because this point has been raised from several countries this has now become the first protocol amendment. See the project website under "Project", "Protocol amendments".

4.) Management issues and other small points

- We have come across some interesting websites that discuss strategies for recruiting participants (and for keeping them in the study). The first, http://blog.getparticipants.com/ has some interesting general points and ideas that could be useful. The second, http://online.wsj.com/article/SB10001424052748703580004576180811400890264.html is specifically about recruiting participants more efficiently and quickly by using existing patient databases. Both speak to the fact that recruiting participants is never easy, but that strategies exist to improve it. Recruiting participants will also be a topic at the kick-off meeting.

- Two small clarifications, because some of you have asked: The lump sum per participant is for *every* participant randomised, also for those assigned to the control group. And if you think you are able to recruit *more* participants than the target number, you are very welcome to do so.

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The next newsletter will appear whenever there is enough to share (that will be soon I'm sure) and I have time to write it (that may take more time). Contributions from you are welcome, as always. Meanwhile, the best of luck with your further progress, and looking forward to see you all very soon in Bergen!

Best wishes

Christian Gold