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Group interventions for adults with ASD

Ela Cernyw
Bangor University

January 2015

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Section 1

Thesis Abstract

The literature review explored group based psychosocial interventions for adolescents and adults with ASD. The interventions detailed in the review addressed many of the reported difficulties of ASD (i.e. social interaction, communication skills, and managing emotional distress). Fifteen studies met the inclusion criteria and almost all studies ($n = 14$) reported improvements in most or all of their targeted outcomes. Our ability to assess the overall benefit of group based psychosocial interventions was limited, due to small sample sizes, variation in study qualities, and the heterogeneous nature of the interventions. Research in this field would benefit from moving in a coherent direction, with researchers developing an intervention and evaluating its effectiveness in large scale controlled studies, rather than numerous researchers publishing pilot or small scale studies.

The empirical paper described a thematic analysis of participants with ASD ($n=4$) and facilitators' ($n=2$) experiences of a social skills intervention. Richly detailed accounts from participants and facilitators described a broad range of individual and group based processes, and allowed a comparison of multiple perspectives. An overarching concept of separate togetherness was identified in the data, which refers to the shared but individual learning experience within and between the participants and the facilitators. Both papers highlight the challenge of generalisation of skills when working with individuals with ASD, and the difficulty of addressing the individual needs of participants in a group intervention. The results suggest that group based psychosocial interventions show promise, however further, longer-term, exploration is needed in order to consolidate the evidence base. The final paper examines the contributions made to theory and clinical practice, whilst outlining areas requiring further research.

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Acknowledgements

I would like to thank Dr Bethan Henderson and Dr Gemma Griffith for their invaluable supervision, support and guidance throughout this project. A special thank you to the individuals who were willing to share their experiences with me. Finally I'd like to thank my fellow trainees, my partner, family and friends for their moral support and encouragement throughout the process of clinical training.

Section 2: Literature Review

**A literature review of group based psychosocial interventions for
adolescents and adults with autism spectrum disorders.**

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Appendix A: Clinical Psychology Review: Guide for authors

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Abstract

This literature review summarises the evidence base for group based psychosocial interventions for adolescents and adults with Autism Spectrum Disorders (ASDs). Fifteen studies met the inclusion criteria, and were summarized and analysed in terms of (a) participants, (b) targeted skills, (c) intervention procedures, and (d) intervention outcomes. The interventions detailed in the review addressed many of the reported difficulties of ASDs (e.g. social interaction, communication skills, and managing emotional distress). Fourteen studies reported improvements in most or all of their targeted outcomes. The interventions employed in the studies were diverse with thirteen studies applying either an adaptation of a standardised social skills program or a social skills group program designed specifically for the research study. Other interventions included an adapted version of an Acceptance and Commitment Therapy based skills group and an adapted version of Mindfulness Based Cognitive Therapy. Despite promising results, our ability to assess the overall benefits of group based psychosocial interventions is limited, due to small sample sizes, variation in study quality and the heterogeneous nature of the interventions. Future research should implement more rigorous methodology e.g. randomised controlled trials with large sample sizes to consolidate the evidence base.

Keywords: autism, asd, group, interventions, adolescents, adults,

Autistic spectrum disorders (ASDs) are pervasive developmental disorders, they include autism, Asperger syndrome (AS), High Functioning Autism (HFA) and Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS). Both the DSM-V (APA, 2013) and ICD 10 (WHO, 1992) diagnostic systems outline a core set of impairments that individuals with ASDs share, namely: difficulties in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours.

The difficulties experienced by individuals with ASDs have considerable heterogeneity. Some people on the spectrum may have very limited language skills whereas others may have proficient language abilities. Some will have a profound/severe level of learning disability whilst others will be of average intelligence or higher (Levy & Perry, 2011). Consequently, some individuals with an ASD are able to live independent lives whereas others require a lifetime of specialist support (Levy & Perry, 2011).

Historically, the prognosis for individuals diagnosed with an ASD in childhood has been poor. Levy and Perry (2011) reviewed the long-term outcomes in adolescents and adults with autism and found that on average 50–60 % of adults with an ASD leave school without educational or vocational credentials, 76 % of adults are unable to find work, and 90–95 % reported being unable to establish meaningful friendships or establish long-term romantic relationships. Similarly, a review of outcomes in adults with an ASD, found that many individuals, including those of normal IQ, were significantly disadvantaged regarding employment, social relationships, physical and mental health, and quality of life (Howlin & Moss, 2012).

Social deficits such as difficulty forming age-appropriate peer relationships, having limited understanding of social cues, reciprocal conversation, understanding others' emotions, and appropriate use of humour remain some of the most difficult areas for individuals with ASDs

(Attwood, 2000). Frequently, the result of these social deficits is social isolation (Tantam, 2000). High-functioning adolescents with ASDs, in particular, become more keenly aware of the difficulties they encounter when interacting with peers (Laugeson et al., 2009). Evidence suggests many individuals with ASDs are interested in forming relationships with others (Humphrey & Lewis, 2008) however a lack of necessary social skills may result in fewer social interactions and increased isolation (Stokes, Newton, & Kaur, 2007).

Adults with ASDs often experience comorbid psychological difficulties, such as depression and anxiety disorders, with co-morbidity rates ranging from 41% to 81% (De Bruin et al., 2007). One possible explanation is that greater self-awareness of social skills difficulties coupled with a desire to develop relationships without the essential skills to do this successfully may lead to the risk of developing co-morbid mood and anxiety disorders (Myles 2003; Tantam 2003). These findings suggest the need for provision of psychosocial interventions to improve the social relationships and psychological wellbeing of this potentially vulnerable population.

Bishop-Fitzpatrick et al. (2013) conducted a systematic review of psychosocial interventions for adults with ASDs. They included a combination of both individual and group based interventions. They found 13 studies, the majority of which were single case studies or non-randomized controlled trials. Most of the studies focused on behavioural techniques (e.g. Applied Behaviour Analysis) or Social Cognition training. The targeted outcomes were a variation of improving participants' communication, social interaction, and flexibility of thinking and behaviour. They reported largely positive effects; however they outlined a need for rigorous development and evaluation of psychosocial treatments for adults with ASDs.

There has been recent interest in group-based interventions for adults with ASDs. Most of these have focused on developing social skills building. Barnhill, Cook, Tebbenkamp, and

Myles (2002) suggested that teaching social skills in a group setting allows participants to develop new skills while using those skills to form relationships within the context of the group. Furthermore fun group activities may also facilitate peer interactions and new friendships (White et al., 2007). Ledford et al. (2008) also reported on the benefits of group based interventions for individuals with ASDs such as providing the opportunity for observational learning to occur, increasing the likelihood of generalization to more natural environments (Ledford et al., 2008).

Group based interventions are economically desirable in the current clinical climate due to their cost and time efficiency (Ledford et al., 2008). Furthermore recent guidelines and recommendations from NICE (2012) recommended that a group-based social learning programme should be utilised with adults with ASDs without a learning disability who have identified problems with social interaction. While evidence is accumulating regarding the benefits of group based psychosocial interventions for adolescents and adults with ASDs, there have been no reviews or meta-analyses conducted to summarize the cumulative evidence base for these approaches. This review of existing literature aims to examine the evidence base of group based psychosocial interventions for adolescents and adults with ASDs, in order to determine themes in treatment approaches and evaluate the evidence of their efficacy.

Method

Search procedure

First, systematic searches were conducted in three electronic databases: PsycINFO, PubMed, and Web of Science. In all three databases the search was limited to articles written in English and published between 1980 and December 2013 in peer-reviewed journals. The

keywords fields in all three databases were searched using various forms and combinations of the terms “autism”, “Asperger syndrome”, “pervasive developmental disorder”, “High functioning autism” “youth”, “adolescents”, “adults”, and “intervention”, “group”, “treatment”, “social skills”, “psychosocial”. Following the database search, the reference lists of the studies that met inclusion criteria were reviewed to identify additional studies for inclusion.

Study selection

The search and exclusion process is illustrated in Figure 1. Initial database searches yielded 245 results, following title evaluations and duplicate extraction, 183 studies were excluded. The abstracts of the 62 remaining studies were read to assess suitability; this led to the exclusion of 34 papers resulting in 28 papers. The full articles of the 28 papers were read, which led to a further 13 papers being excluded, therefore leaving fifteen papers evaluated as appropriate and meeting the eligibility criteria to be included in the review.

<insert figure 1>

Eligibility criteria (inclusion and exclusion criteria)

Studies were included if they met the following inclusion criteria:

1. The study must have appeared in an English-language peer reviewed journal.
2. Papers published between 1980 and 2013.
3. All of the participants had to be 13 years or older.
4. Participants had a diagnosis of an ASD (including Asperger’s, HFA, PDD-NOS) based on either self-report, previous assessment by a physician, or independent verification during the study.

5. In order to ensure that participants did not have a learning disability, participants had a Full scale IQ or Verbal IQ of 70 or above. In studies in which IQ data were not reported, participants had to be diagnosed with Asperger syndrome (AS), or be described as “high functioning”.
6. The psychosocial intervention of the study had to be in a group format. Psychosocial interventions were defined as those that target communication, social interaction, flexibility of thinking and behaviour, quality of life and managing psychological difficulties (Odom et al. 2010).

Data extraction

Each included study was summarized in terms of the following variables: (a) number, age, gender, diagnosis, IQ of participants, and number of groups in the study; (b) intervention type, duration and length, (c) targeted skill and measures used, (d) experimental design and outcomes as reported by the authors and, (e) the strength and weaknesses of the studies including measures on follow-up (FU), generalization (Gen), social validity (SV), inter-observer agreement (IOA), and treatment fidelity (TF). Details of these categories can be seen in Table 1.

Treatment outcomes

Treatment outcomes were classified as positive, negative or mixed (Machalicek et al., 2008; Palmen et al., 2012). Results were classified as “positive” if significant group improvements were found in all the targeted skills. Positive outcomes were reported for six studies. Results were classified as “mixed” if some but not all of the targeted skills improved, mixed results were reported by eight studies. Results were classified as “negative” where no significant group improvement was shown following the intervention, one study did not show improvement following intervention.

Design and certainty of evidence

Design and other methodological characteristics were considered when evaluating the quality of evidence for each included study. The certainty of evidence hierarchy originally developed by Smith (1981) and adapted by Ramdoss et al. (2011) and Palmen et al. (2012) was used in which studies are rated as either ‘conclusive’, ‘preponderant’, or ‘suggestive’ in their quality of evidence.

Within the lowest level of certainty, classified as suggestive evidence, studies did not use a true experimental design (pre-post study with no control group); or did not fulfil all of the criteria for the preponderant level of certainty, ten studies were assessed as having a suggestive certainty of evidence. The second level of certainty, classified as preponderant evidence, contained studies utilizing a true experimental design and the following four qualities: (a) adequate inter-observer agreement outcomes (i.e., 80% or higher agreement or reliability in at least 20% of sessions), (b) adequate treatment fidelity measures/outcomes, (c) operationally defined dependent measures, and (d) sufficient detail on intervention procedures to enable replication. Two studies were rated as providing a preponderant level of certainty of evidence. Three studies were assessed at the highest level of certainty, classified as conclusive, contained studies that (a) utilized true experimental designs, (b) contained the four qualities of the preponderant level and (c) contained design features that provided at least some control for alternative explanations for intervention outcomes.

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Results

Participants

A total of 297 individuals participated in the studies. The sample size in each study ranged from three to 49, and 12 studies had more than six participants. Among the 297 participants, 77 were female (26%) and 220 were male (74%). Nine studies included participants of 16 years or older, one had a range of 14 to 35 years, and five studies included participants between 13 and 21 years old. 135 participants were diagnosed with HFA (45%), 98 participants were diagnosed with Asperger's syndrome (33%), 43 were diagnosed with ASDs (14%) and 21 were diagnosed with PDD-NOS (8%). Across studies, seven reported IQ scores for the participants, with a mean IQ of 103.7 (range 91 to 112). For the other eight studies, no IQ scores were reported, however all participants had a diagnosis of Asperger syndrome (AS), or described the participants as "high functioning", and/or have age appropriate language skills (as stated in the inclusion criteria).

Data collection

Nine studies used self-report measures. In five studies, data was collected using questionnaires completed by caregivers or teachers. Data on targeted skills was also collected through direct observation in eight studies. For example, social skill interactions were measured during role play scenarios, and also through observation during group contributions.

The outcome measures used were extremely diverse, and many of studies reported difficulty finding measures which were validated for the population and were sensitive enough to identify subtle changes in behaviour or skills. Four studies used a combination of self-report and informant (parent/caregiver/teacher) measures at pre and post intervention (Gantman et

al., 2012, Laugeson et al., 2009, Mitchell et al., 2010, Pahnke et al., 2013). They reported no significant differences between informant and participant scores on the outcome measures.

Interventions and Outcomes

Intervention duration. The duration of the interventions varied considerably between studies, in relation to both session duration and overall length. Sessions ranged from 40 minutes (Pahnke et al., 2013) to 2-3 hours weekly (Fullerton and Coyne, 1999). Fourteen studies undertook weekly interventions, and one offered monthly sessions (Howlin and Yates, 1999). Interventions lasted between 6 weeks (Pahnke et al., 2013) and 12 months (Howlin and Yates, 1999). The number of participants within each group also varied, ranging from three (Palmen et al., 2008) to 10 in a group (Howlin and Yates, 1999; Mesibov, 1984), with the mean number of participants in each group being six. Due to the variable nature of the interventions, it was not possible to determine whether duration or frequency of the interventions affected their effectiveness.

The interventions and their outcomes will be discussed according to the skills targeted, namely: (a) social interaction and communication skills; (b) management of emotional distress/ enhancement of quality of life; and (c) enhancement of social skills and management of emotional distress combined. The studies will be discussed in terms of immediate and follow up outcomes, where possible, and generalizability of skills learnt.

Interventions targeting social interaction and communication skills. Nine studies targeted social skills, four focused on social interaction (building close relationships, improving friendships, and improving current social functioning), and the other five targeted specific communication techniques (initiating and maintaining conversations, or improving non-verbal communication).

Improving social interaction. Four studies targeted improving social interaction. One reported positive results (Gantman et al., 2012) and three reported mixed results (Turner-Brown et al., 2008; Laugeson et al., 2009; Hillier et al., 2007). An RCT undertaken by Gantman et al., (2012) implemented an adaptation of an existing standardised social skills group program with 17 young adults and reported that loneliness significantly reduced and social skills knowledge improved following the 14 weeks intervention. Additionally, caregivers reported significant improvements in participants' overall social skills, social responsiveness, empathy, and frequency of get-togethers. The small sample size and lack of follow up, however, make it difficult to infer conclusions from the results.

Turner-Brown et al. (2008) implemented a modified treatment manual of a previously validated intervention, Social Cognition and Interaction Training (SCIT) and compared it to a treatment as usual (e.g. individual therapy, job skills coaching) control group. The intervention targeted social functioning and social cognition (theory of mind). Mixed results were reported, participants in the SCIT group showed significant improvement in theory-of-mind skills, however, no significant improvement was found on the social functioning measures. Turner-Brown et al. (2008) suggested that the outcome measures used may not have been sensitive enough to identify changes, and that the material covered may not have been relevant to individuals with HFA, indicating that the content of the intervention may need further modification.

Mixed results were found by both Laugeson et al. (2009) and Hillier et al. (2007), who implemented adaptations of existing ASD specific standardised social skills group programs (PEERS intervention and the Aspirations intervention respectively). Laugeson's et al. (2009) RCT reported mostly positive results following a 12-week intervention. They demonstrated that teens in the treatment group showed significant improvement in their knowledge of

social skills, increased frequency of hosted get-togethers, and improved overall social skills as reported by parents, with successful generalisation of skills. No significant improvements were found on invited get-togethers post interventions.

In the study by Hiller et al. (2007) participants showed significantly improved results on an empathy measure following an 8 week intervention, however there were no significant improvements on the peer relations scale or the measure focusing on autism spectrum traits. The study lacked methodological rigour due to the small sample size and use of a pre-post design without a control group, therefore it is unclear whether the treatment effect was genuine or due to confounding variables.

Both Gantman et al. (2012) and Laugeson et al. (2009) implemented versions of the same intervention (The UCLA PEERS Program). A parent/caregiver group was also incorporated to help with generalizability of skills, as the participants were encouraged by parents/caregivers to practice their skills outside of the group. This may have been a key factor in the effectiveness of the interventions and highlights the importance of considering including caregivers/parents in interventions and also providing opportunities for participants to practice their skills outside of the group setting (e.g. during get-togethers or social events).

In terms of duration of interventions, Laugeson et al. (2009), Gantman et al. (2012) and Turner-Brown et al. (2008) had 90 minute sessions over a period of 12-18 weeks, whereas Hillier et al. (2007) had 60 minute sessions over a period of eight weeks. As the interventions were targeting improving social interaction and developing skills to initiating relationships, perhaps a longer duration of session and overall intervention was needed to provide opportunities to develop and cultivate close friendships. However, the variation of interventions and outcomes targeted make it difficult to draw any definitive conclusions.

In summary, the results suggest that both bespoke and existing social skills programs may have some benefit in improving social interaction in adolescents and young adults with ASDs. Including caregivers/parents and providing opportunities for participants to practice their skills outside of the group setting may be important elements to consider when choosing/designing future interventions, as it may help the participants to generalise the skills learnt to everyday life. The methodological limitations and small sample sizes of some of the studies, however, restrict the conclusions that can be drawn. Gantman et al. (2009) and Laugeson et al. (2012) used a more rigorous randomised control design, but as they did not collect any follow-up data, the long term effectiveness of the interventions have not been established. Further exploration of the long term benefits of the interventions as well as replication with larger sample sizes is needed before any definitive conclusions can be drawn.

Increasing specific communication skills. Five studies focused on improving specific communication skills, such as initiating and maintaining conversations, improving non-verbal communication, and picking up on social cues. Palmen et al. (2008) and Mesibov (1984) reported positive results whereas mixed results were found by Dotson et al. (2010), and Howlin and Yates (1999). One study did not demonstrate any significant improvement following the intervention (Barnhill et al., 2002).

Palmen et al. (2008) used a small-group training course to improve question-asking skills during tutorial conversations. The intervention consisted of providing feedback and self-management strategies to nine adolescents with HFA. All participants demonstrated significant improvement in effective question asking following intervention. The results indicated successful generalisation of skills and the effects were mostly maintained at one month follow up. Palmen et al. (2008) used several strategies to promote generalisation, a self-management strategy and common stimuli (e.g., flowchart to follow necessary steps of

effective question asking). They also provided opportunities for participants to practice their skills every week with a personal tutor.

Palmen et al. (2008) focused solely on one social skill- question asking. Narrowing the focus to a specific social skill may have been an important component of the effectiveness of the study. Focusing on one skill is not as time and cost efficient as focusing on various social skills, however, it may be a necessary process to ensure that individuals with ASDs are able to develop, maintain, and generalise the skills. Palmen et al. (2008) also used a multiple baseline design across three groups (3 participants in each group), however the small sample size of the study mean that caution should be taken when interpreting the results. The narrow focus of the intervention in this study makes it difficult to directly compare with other studies in the review that focused on a wider range of outcomes.

Positive results were also reported in the study by Mesibov (1984), following a 12- week bespoke social skills program. Participants showed considerable improvement in conversation skills following the intervention based on a role-played social situation, self-report measures, and a direct assessment of conversational skills. The study failed to report the outcomes of the self-report measures, reporting only qualitative accounts of the intervention's effectiveness. The small sample size, absence of a control group and lack of treatment fidelity procedures mean that caution should be taken when interpreting the results of the study.

Both Howlin and Yates (1999) and Dotson et al. (2010) reported mixed results following implementing bespoke social skills programs. The results of both studies indicated some improvement on conversation skills following intervention for some but not all participants. Additionally in the study of Dotson et al. (2010), the improvements for some individuals were maintained at 3 months follow up, and there was also partial generalisation of skills.

The small sample size of four in the study of Dotson et al. (2010) makes it difficult to generalise the outcomes to a wider population. Howlin and Yates (1999) implemented a non-controlled design and no measures of treatment fidelity were undertaken. Without measures to establish treatment fidelity, and a lack of a control group, the outcomes reported may have been as a result of an unintended treatment by-product and not due to the intervention itself. The small sample sizes and methodological limitations reported here, constrain the conclusions that can be drawn about the effectiveness of these interventions.

In the study of Barnhill et al. (2002) an ASD-specific adaptation of the program “Teaching Your Child the Language of Social Success” (Duke, Nowicki, & Martin, 1996) was implemented. The study reported some improvement in communication skills post intervention, however, these did not reach statistical significance. The authors suggested two possible reasons for this. First, the eight-week intervention may have been too short for skills to develop and generalise to other situations. Second, generalization of intervention effects may have been hampered because the social skills instruction was conducted in the same environment each week.

The duration of the interventions targeting specific communication skills varied between 7 weeks and 12 months, with positive and mixed results reported. The range of interventions and targeted outcomes make it difficult to explore the relationship between intervention duration and its effectiveness. To summarise, although it appears that bespoke social skills programs were more effective in improving communication than existing standardized social skills programs, the methodological limitations of the studies such as small sample sizes, uncontrolled designs, limited follow up data and no measures of treatment fidelity make it impossible for this conclusion to be drawn. Despite this, there are certain elements within the interventions that appear to have contributed to the success of the interventions. For instance,

focusing on one skill, using visual prompts, and providing opportunities to practice and generalise skills appear to be important elements to consider incorporating in future interventions.

Management of emotional distress/ improving quality of life. Two studies targeted management of emotional distress and/or improving quality of life. Both Pahnke et al. (2013) and Spek et al. (2013) implemented adapted versions of existing evidence based interventions for managing mental health difficulties. Pahnke et al. (2013) explored the effectiveness of an adapted version of Acceptance and Commitment Therapy in reducing emotional distress in adolescents and young adults with ASDs. They reported a significant reduction in levels of stress, hyperactivity and emotional distress and increased pro-social behaviour in the treatment group following intervention. These changes were stable or had improved further at the 2-month follow-up. Pahnke et al. (2013) study was a quasi-experimental design and had a small sample size. The study included a large age range of participants, and two of the measures used were out of the valid age range for the older participants. Furthermore, lack of systematic assessment of treatment fidelity (e.g. rating tapes of treatment sessions or using therapist checklists) meant that the specific ACT procedures and modifications were not clearly measured, and thus, the degree to which the procedures were implemented cannot be determined. The results must therefore be interpreted with caution due to these methodological limitations.

Spek et al. (2013) implemented an adapted ASD-specific Mindfulness Based Cognitive Therapy intervention and reported a significant reduction in depression, anxiety and rumination in the intervention group when compared to the control group. Furthermore, positive affect increased in the intervention group, but not in the control group. Although

Spek et al's. (2013) study was a randomised controlled trial, without replication studies and follow up data the true effectiveness and the long term effects have not yet been explored.

The interventions in the studies of Spek et al. (2013) and Pahnke et al. (2013) required the participants to practice the skills learnt at home on a daily basis, which may have helped with generalisation of skills. Both studies made modifications to the existing interventions, such as considering information processing deficits, and avoiding metaphors or ambiguous language. This may have been an essential component of the interventions' effectiveness, and is something that should be considered in future studies.

The studies demonstrated promising outcomes of using modified versions of existing evidence based interventions for reducing emotional distress in adolescents and young adults with ASDs. Providing opportunities for generalisation and adapting the interventions to be 'ASD friendly' also appear to have been an important component of the interventions. Further research with larger sample sizes are needed to consolidate the evidence base.

Enhancement of social skills and management of emotional distress combined.

Four studies focused on both enhancement of social skills and management of emotional distress in a single intervention. Hillier et al. (2011) examined the effectiveness of an existing standardised social skills group program on reducing depression and anxiety and improving peer relations in adolescents and young adults with ASDs. They reported mixed but mostly positive results with significant reduction in depression and anxiety but no significant improvement in peer relations. No follow up data was collected therefore it is unclear how sustainable the effects were in the long term. The results of the study provide initial promise in the use of existing social skills group programs in reducing mental health difficulties in adolescents and adults with ASDs. The study was a pre-post design with no

control group; therefore the lack of methodological robustness limits any conclusions that can be made.

Mitchell et al. (2010) explored the effectiveness of an ASD specific adapted version of an existing standardised social skills group program to improve social skills and quality of life in three adolescents with ASDs. The study reported mixed results, with positive outcomes maintained at follow up. Partial generalisation of skills was also reported. The small sample size of the study means that there are limitations to the conclusions that can be made.

Fullerton and Coyne (1999) also used an adapted version of an existing standardised group program and explored its effectiveness in developing knowledge and skills for self-determination in young adults with ASDs. They reported positive results following the intervention, all participants showed improvement in self-awareness and coping skills for their sensory, cognitive, and social difficulties, with partial generalisation of skills. No follow up data was reported and the pre-post design mean that limited conclusions can be drawn from the results. Participants reported that the use of visual prompts was very helpful and is something that should be considered in future studies.

Lastly Tse et al. (2007) used a bespoke social skills intervention with adolescents with ASDs. They reported significant pre- to post-treatment gains on measures of both social competence and '*problem behaviours*' associated with ASDs. They also reported partial generalisation of skills by some participants. Significant improvements were also found for '*problem behaviours*' associated with AS/HFA, including affect regulation problems, anxiety, self-isolation, stereotypic behaviours and self-injurious behaviours. Larger, controlled studies would be valuable to explore the effectiveness of this type of intervention.

Both bespoke and adapted versions of an existing standardised social skills group program appear promising in targeting enhancement of social skills and management of emotional distress in a single intervention. The uses of visual prompts were reported to be helpful and are something to consider in future studies. Small sample sizes and uncontrolled designs make it difficult to evaluate the true effectiveness of the interventions.

In summary both bespoke and adapted versions of an existing standardised social skills group program and adapted existing mental health interventions appear promising in improving social interaction, specific communication skills and management of emotional distress in adolescents and adults with ASDs. Further large scale research is needed to consolidate the evidence base.

All of the studies included in the review including those that reported no significant improvement post intervention reported positive social validity by the participants and caregivers. The interventions were reported as mostly acceptable and effective in improving social skills or managing emotional distress by the participants and caregivers; however in some studies the measures did not reflect this. Further research exploring appropriate use of measures and exploring creative ways of capturing change within this population is also needed.

Discussion

The interventions detailed in this review targeted many of the reported difficulties of ASDs (e.g. social interaction, communication skills, and managing emotional distress). Almost all studies ($n = 14$) reported improvements in most or all of their outcomes. However, our ability to assess the overall benefit of group based psychosocial interventions is limited due to small sample sizes, variation in study quality and the heterogeneous nature of the

interventions. The skills targeted within the studies reflect the broad difficulties experienced by individuals with ASDs. However, the broadness of the skills targeted also make it difficult to compare the studies or draw conclusions on the interventions' overall effectiveness.

The types of intervention implemented within the studies were extremely diverse with thirteen studies applying either an adaptation of a standardised social skills program or a bespoke social skills program. Other interventions included an adapted version of an Acceptance and Commitment Therapy based skill group and an adapted version of a Mindfulness Based Cognitive Behavioural therapy. Positive outcomes were reported across a range of different interventions, therefore, at this stage, there is no evidence that supports the effectiveness of one specific type of intervention over another.

It has been widely documented that individuals with ASDs have difficulty generalising skills learnt within a classroom setting to a more natural setting, and as a result many researchers have cautioned against skills training for individuals with ASDs outside of natural settings (Bellini et al., 2007; Gresham et al., 2001). All six of the studies that reported positive outcomes provided opportunities for the individuals to practice newly learned skills in a natural setting, and found that on the whole skills were generalised. This suggests that the main skills training intervention can occur within a classroom setting but that individuals are likely to benefit from opportunities to practice these skills in their natural environments.

Over half of the studies had more than one component to their interventions, such as an addition of a parent component, extra individual or coaching sessions, or homework tasks. Although other studies without these components reported positive results, these additions appear to have helped with generalizability of skills. Inclusion of parents/caregivers/tutors/homework in the interventions promoted generalisation as the participants were encouraged

to practice their skills in other situations. This highlights the importance of both including caregivers/parents in interventions and also providing opportunities for participants to practice their skills outside of the group setting (e.g. during get-togethers or social events) although it is difficult to say for sure given the paucity of evidence.

The results highlight the importance of modifying interventions to make them accessible and useful for individuals with ASDs. Studies reported using visual prompts, avoiding metaphors or ambiguous language, and considering information processing deficits. This may have been an essential component of the interventions' effectiveness, and is something that should be considered when developing future interventions.

The outcome measures used were extremely diverse, and many studies reported difficulty finding measures which were validated for the population and sensitive enough to identify subtle changes in behaviour or skills. Outcomes within this population appear to be subtle, difficult to measure, and not directly tapped by questions on self-report measures, requiring more rigorous assessment from multiple components. Future studies should consider capturing outcomes from multiple perspectives, including third party informants who are not directly involved in the intervention. There is also a need to develop tailored outcome measures for this population to capture accurate representations of the difficulties faced by adolescents and adults with ASDs and also capture potential changes following interventions.

All fifteen of the studies reported that some social relationships among group members were developed and maintained during the course of the group. Many participants also reported on the benefits of attending a group such as interacting with others with an ASD, and having the opportunity to discuss challenging personal issues with others who were able to relate to them. Unfortunately most studies did not capture this information in a formal way. Future studies should consider developing ways of capturing this information, for example with

qualitative data. Knowing what participants find most helpful would further help refine future interventions.

Limitations

Despite evidence of the promising benefits of group based psychosocial interventions for adolescents and adults with ASDs, there are significant limitations to the current evidence base. While an extensive search of the literature available on group psychosocial interventions for adults with ASDs was conducted; only 15 studies were found. Our ability to assess the benefit of group based psychosocial interventions is limited, due to small sample sizes, variation in study qualities and the heterogeneous nature of the interventions. Due to the heterogeneous nature of the studies a meta-analysis was not possible; consequently clear estimates of effect size for different types of psychosocial interventions are not yet available.

Another limitation was that the review included participants with ASDs, AS/HFA, and PDD-NOS without reporting results according to each diagnosis separately. Whilst these are currently conceptualised as existing on a spectrum, there are known differences between the presentations of each. The implications for this current review is that findings should be interpreted with caution as the effectiveness of psychosocial interventions may differ between diagnoses. A certainty of evidence analysis was undertaken on each study; however more rigorous analysis of the studies' methodology using more standardised methods would strengthen the conclusions made in the review.

Future studies

This review of the evidence base for group based psychosocial interventions in adolescents and adults with ASDs is informative in guiding future studies. Future research should implement more rigorous methodology e.g. randomised controlled trials with large numbers

of participants. Additional naturalistic as well as standardized assessment tools are also needed in this field. Research in this field needs to move in a coherent direction, with researchers building upon an intervention and evaluating its effectiveness in large scale controlled studies, rather than numerous researchers publishing pilot or small scale studies of different interventions.

Conclusion

While the number of studies which comprise the evidence base of group based psychosocial interventions for adolescents and adults with ASDs is small, almost all of the studies included in this review report a mainly positive benefit to study participants. This suggests that group based psychosocial interventions for adolescents and adults with ASDs may be beneficial for this population in terms of improving social skills, and managing emotional distress more effectively. However, there is a need for more innovative and methodologically rigorous intervention studies before any firm conclusions can be drawn.

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References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Attwood, T. (2000). Strategies for improving the social integration of children with Asperger syndrome. *Autism, 4*(1), 85-100.
- Barnhill, G. P., Cook, K. T., Tebbenkamp, K., & Myles, B. S. (2002). The effectiveness of social skills intervention targeting nonverbal communication for adolescents with Asperger syndrome and related pervasive developmental delays. *Focus on Autism and Other Developmental Disabilities, 17*(2), 112-118.*
- Bellini, S., Peters, J. K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education, 28*(3), 153-162.
- Bishop-Fitzpatrick, L., Minshew, N. J., & Eack, S. M. (2013). A systematic review of psychosocial interventions for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(3), 687-694.
- de Bruin, E. I., Ferdinand, R. F., Meester, S., de Nijs, P. F., & Verheij, F. (2007). High rates of psychiatric co-morbidity in PDD-NOS. *Journal of Autism and Developmental Disorders, 37*(5), 877-886.
- Dotson, W. H., Leaf, J. B., Sheldon, J. B., & Sherman, J. A. (2010). Group teaching of conversational skills to adolescents on the autism spectrum. *Research in Autism Spectrum Disorders, 4*(2), 199-209.*
- Fullerton, A., & Coyne, P. (1999). Developing skills and concepts for self-determination in young adults with autism. *Focus on Autism and Other Developmental Disabilities, 14*(1), 42-52.*
- Gantman, A., Kapp, S. K., Orenski, K., & Laugeson, E. A. (2012). Social skills training for young adults with high-functioning autism spectrum disorders: A randomized controlled pilot study. *Journal of Autism and Developmental Disorders, 42*(6), 1094-1103.*
- Gresham, F. M., Sugai, G., & Horner, R. H. (2001). Interpreting outcomes of social skills training for students with high-incidence disabilities. *Exceptional Children, 67*(3), 331-344.*
- Hillier, A., Fish, T., Cloppert, P., & Beversdorf, D. Q. (2007). Outcomes of a social and vocational skills support group for adolescents and young adults on the autism spectrum. *Focus on Autism and Other Developmental Disabilities, 22*(2), 107-115.*
- Hillier, A. J., Fish, T., Siegel, J. H., & Beversdorf, D. Q. (2011). Social and vocational skills training reduces self-reported anxiety and depression among young adults on the autism spectrum. *Journal of Developmental and Physical Disabilities, 23*(3), 267-276.*
- Howlin, P., & Yates, P. (1999). The potential effectiveness of social skills groups for adults with autism. *Autism, 3*(3), 299-307.*
- Howlin, P., & Moss, P. (2012). In Review-Adults with autism spectrum disorders. *Canadian Journal of Psychiatry, 57*(5), 275.

- Humphrey, N., & Lewis, S. (2008). Make me normal' The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism, 12*(1), 23-46.
- Laugeson, E. A., Frankel, F., Mogil, C., & Dillon, A. R. (2009). Parent-assisted social skills training to improve friendships in teens with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39*(4), 596-606.*
- Ledford, J. R., Gast, D. L., Luscre, D., & Ayres, K. M. (2008). Observational and incidental learning by children with autism during small group instruction. *Journal of Autism and Developmental Disorders, 38*(1), 86-103.
- Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders, 5*(4), 1271-1282.
- Machalicek, W., O'Reilly, M. F., Beretvas, N., Sigafoos, J., Lancioni, G., Sorrells, A., & Rispoli, M. (2008). A review of school-based instructional interventions for students with autism spectrum disorders. *Research in Autism Spectrum Disorders, 2*(3), 395-416.
- Mesibov, G. B. (1984). Social skills training with verbal autistic adolescents and adults: A program model. *Journal of Autism and Developmental Disorders, 14*(4), 395-404.*
- Mitchel, K., Regehr, K., Reaume, J., & Feldman, M. (2010). Group social skills training for adolescents with Asperger Syndrome or high functioning autism. *Journal on Developmental Disabilities.**
- Myles, B. S. (2003). *Social Skills Training for Children and Adolescents With: Asperger Syndrome and Social Communication Problems*. Autism Asperger Publishing Company.
- NICE (2012). *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*. Retrieved from <http://www.nice.org.uk/CG142>
- Odom, S. L., Collet-Klingenberg, L., Rogers, S. J., & Hatton, D. D. (2010). Evidence-based practices in interventions for children and youth with autism spectrum disorders. *Preventing School Failure: Alternative Education for Children and Youth, 54*(4), 275-282.
- Pahnke, J., Lundgren, T., Hursti, T., & Hirvikoski, T. (2013). Outcomes of an acceptance and commitment therapy-based skills training group for students with high-functioning autism spectrum disorder: A quasi-experimental pilot study. *Autism, 1362361313501091.**
- Palmen, A., Didden, R., & Arts, M. (2008). Improving question asking in high-functioning adolescents with autism spectrum disorders Effectiveness of small-group training. *Autism, 12*(1), 83-98.*
- Palmen, A., Didden, R., & Lang, R. (2012). A systematic review of behavioral intervention research on adaptive skill building in high-functioning young adults with autism spectrum disorder. *Research in Autism Spectrum Disorders, 6*(2), 602-617.
- Ramdoss, S., Mulloy, A., Lang, R., O'Reilly, M., Sigafoos, J., Lancioni, G., et al. (2011). Use of computer-based interventions to improve literacy skills in students with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders, 5*, 1306-1318.

- Smith, N. (1981). The certainty of evidence in health evaluations. *Evaluation and Program Planning*, 4, 23–278.
- Spek, A. A., van Ham, N. C., & Nyklíček, I. (2013). Mindfulness-based therapy in adults with an autism spectrum disorder: A randomized controlled trial. *Research in Developmental Disabilities*, 34(1), 246-253.*
- Stokes, M., Newton, N., & Kaur, A. (2007). Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 37(10), 1969-1986.
- Tantam, D. (2000). Psychological disorder in adolescents and adults with Asperger syndrome. *Autism*, 4(1), 47-62.
- Tantam, D. (2003). The challenge of adolescents and adults with Asperger syndrome. *Child and Adolescent Psychiatric Clinics of North America*, 12(1), 143-163.
- Tse, J., Strulovitch, J., Tagalakis, V., Meng, L., & Fombonne, E. (2007). Social skills training for adolescents with Asperger syndrome and high-functioning autism. *Journal of Autism and Developmental Disorders*, 37(10), 1960-1968.*
- Turner-Brown, L. M., Perry, T. D., Dichter, G. S., Bodfish, J. W., & Penn, D. L. (2008). Brief report: Feasibility of social cognition and interaction training for adults with high functioning autism. *Journal of Autism and Developmental Disorders*, 38(9), 1777-1784.*
- White, S. W., Keonig, K., & Scahill, L. (2007). Social skills development in children with autism spectrum disorders: A review of the intervention research. *Journal of Autism and Developmental Disorders*, 37(10), 1858-1868.
- World Health Organization. (1993) *The ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research*. Geneva, Switzerland: World Health Organization;36-40.

*- included studies in literature review

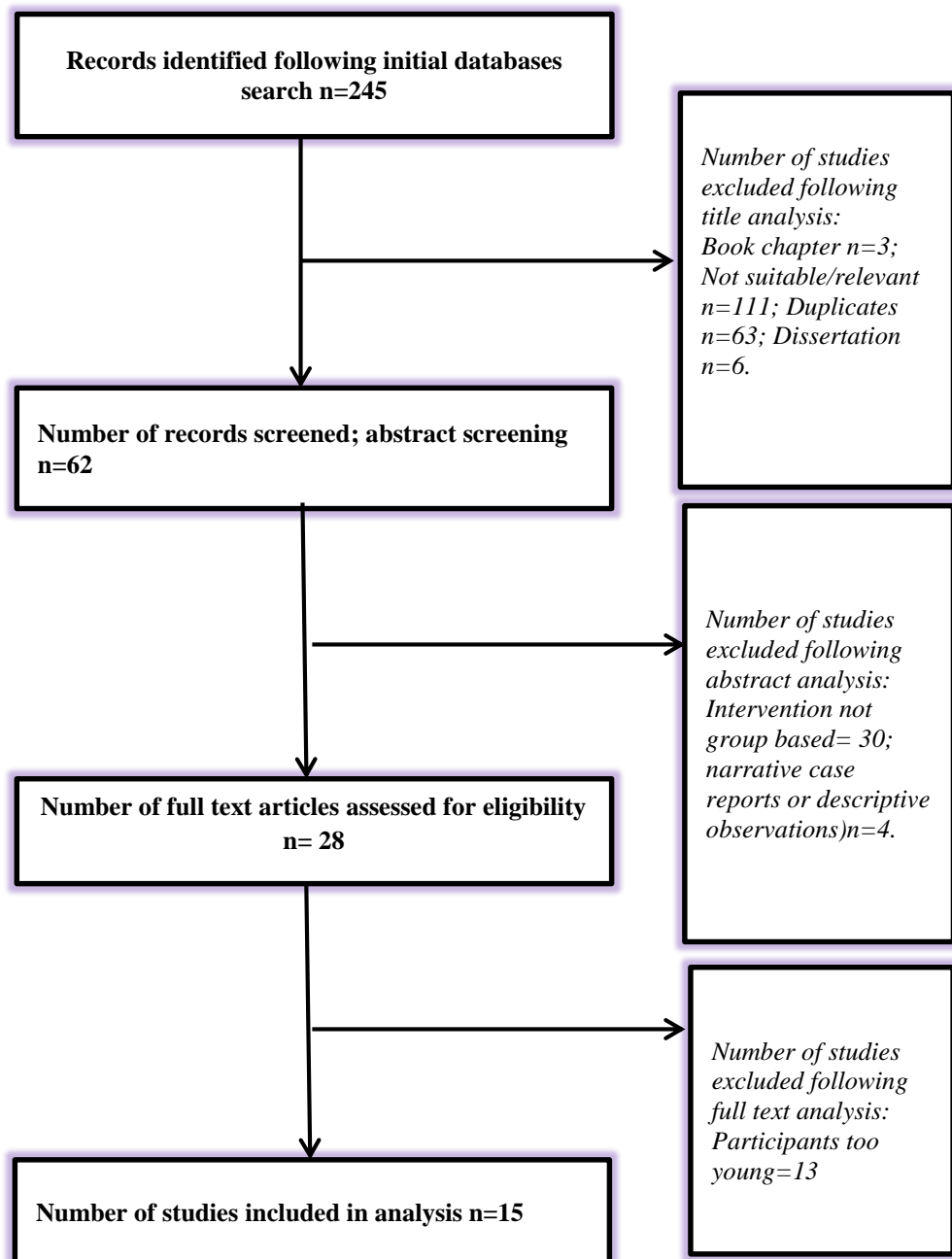
Figure 1: Flow chart of selection process

Table 1: Summary of studies exploring the effectiveness of group based psychosocial interventions for adolescents and adults with ASD.

<i>Study</i>	<i>N</i> <i>Age</i> <i>Gender</i> <i>Diagnosis</i> <i>IQ</i> <i>N of groups</i>	<i>Intervention</i> <i>Duration and length</i>	<i>Targeted skill</i> <i>Measures used</i>	<i>Design and outcome</i>	<i>Strengths and weaknesses</i>
<i>Interventions targeting social interaction and communication skills (more focus on social interaction)</i>					
Gantman et al (2012) USA	17 18-23 12 Males (Treatment-9; delayed- 8) 4- ASD 11- Aspergers 2- PDD-NOS Mean IQ- 102	The UCLA PEERS for Young Adults Program. Parent/caregiver assisted 14 weeks (90 mins)	Enhancement of social interaction and communication Primary outcome measures: 1- Social Responsiveness scale- carer 2- Social skills rating system- carer 3- Social and emotional loneliness scale for adults- self Secondary outcome measures: 1- Empathy Quotient- caregiver 2- Quality of Socialization Questionnaire- caregiver and self 3- Social skills inventory- self report 4- Test of young adults social skills knowledge- self	Design: RCT Outcome: Positive All significant Main effect of group differences, Treatment group improved significantly more than delayed control group p<.02	Follow up: no Generalization: yes Social validity: no Inter observer agreement: no Treatment fidelity: yes Certainty: preponderant
Hillier et al (2007)	13 18-23 11 Males ASD-1 PDD-NOS-4 Asperger's-8 Mean IQ- 108.88 2 groups	Aspirations group intervention Parent self-directed support group 8 weeks 1h	Enhancement of social interaction and communication Self-report: 1- -Index of Peer relations (IPR) 2- -The Autism spectrum quotient (ASQ) 3- -The Empathy Quotient. (EQ) Observations: Observing whether group contributions increased in frequency.	Design: Pre-post Outcome: Mixed IPR- non sig ASQ- non sig EQ- sig Observations- sig	Follow up: no Generalization: no Social validity: yes Inter observer agreement: yes -adequate Treatment fidelity: no Certainty: suggestive
Laugeson et al (2009) USA	33 28 Males 13-17 (17-treatment group 16 delayed	The UCLA PEERS program Parent assisted 12 weeks (90 mins)	Enhancement of social interaction and communication Outcome measures 1- Social Skills rating system (SSRS) 2- Quality of play questionnaire (QOPQ) 3- Test of adolescent social skills knowledge- revisited	Design: RCT Randomly assigned to treatment or delayed treatment Outcome: Mixed Improvement was demonstrated on 4/12 outcome measures.	Follow up- no Generalization- yes, Social validity-no Inter observer agreement-no Treatment fidelity- yes Certainty: conclusive

	treatment group)		4- Friendship Qualities Scale		
	HFA- 23 Aspergers-9 PDD NOS-1		SSRS- parent and teacher QOPQ- self and parent		
	Mean IQ- 92.15				
	5 groups				
Turner Brown et al (2008) USA	11 25-55 10 Males (Treatment – 6; TAU-5) 11- ASD Mean IQ- 112	Social Cognition and Interaction Therapy (SCIT): 18 weeks (90 mins)	Enhancement of social interaction and communication Social Functioning: 1. Social skills performance assessment SSPA 2. Social Communication skills questionnaire SCSQ Social cognition: 1. Face Emotion Identification Test (FEIT) 2. The hinting task	Quasi experimental Outcome: Mixed SSPA-non sig SCSQ-non sig Hinting task- sig FEIT- sig Relative to TAU group	Follow up: no; Generalization: no; Social validity: no Inter observer agreement: yes Treatment fidelity: no Certainty: suggestive
Interventions targeting social interaction and communication skills (more focus on communication)					
Barnhill et al (2002) USA	8 7 Males 13-18 Asperger's- 6 PDD-NOS-1 HFA- 1 IQ not available, All reported to be of high verbal ability	Adapted from Teaching your child the language of social success. 8 weeks (1h)	Enhancement of social interaction and communication 1. Diagnostic analysis of nonverbal accuracy 2 (pre-post).	Design: Pre-post Outcome: Negative No sig diff between pre and post.	Follow up- no Generalization- no Social validity- yes Inter observer agreement- no Treatment fidelity- no Certainty: suggestive
Dotson et al (2010) USA	4 2 Males 13-18 ASD-4	Social skills group (SSG): Concept instruction, task-analyses, modelling, response identification, role-play, social reinforcement, corrective feedback using verbal Prompting.	Enhancement of social interaction and communication Conversation skills: (a) conversation basics, i.e., eye contact, voice tone, distance, body	Design: multiple-probe design in which all three skills were probed at the beginning of the study. Outcome: Mixed	Follow up: yes 3 months; Generalization: yes; Social validity: no Inter observer agreement: yes Treatment fidelity: yes Certainty: conclusive

	Autism-1 Aspergers-1 PDD NOS-2	(3 hours; 1.5 per session, twice weekly)	posture (b) delivering positive feedback (c) answering/asking open-ended questions	All participants met mastery criteria for 2/4 skills.	
		IQ- not reported	The dependent variable in the study was the performance of the individual skill steps by the participants during the three types of probes.		
Howlin and Yates (1999) England	10 All Males 19-44 10- Aspergers Mean IQ- 109.	Social skills group: 12 months (2 ½ hours each month)	Enhancement of social interaction and communication 1. Changes in conversational ability – video recordings of simulated social activities, pre-post group.	Design: Pre-post Outcome: Mixed Mean pre-post data on two simulated social activities reveal significant improvements in 2/4 skills.	Follow up: no; Generalization: no; Social validity: yes Inter observer agreement- yes Treatment fidelity- no Certainty: suggestive
Mesibov (1984) USA	15 11 Males 14-35 Autism IQ – score not available	4 parts: Group discussion Listening and talking Role playing Appreciation of humour 12 weeks (60 mins) After 30 mins individual session)	Enhancement of social interaction and communication 1. Role play social situations 2. Self-report measures: Piers-Harris Children's Self-Concept Scale. 3. A self-report rating form was also used (LaGreca & Mesibov, 1981) to determine how anxious they felt in social situations.	Design: pre-post Results: Positive 1. Role play: showed considerable improvement in initiating and maintaining a 1:1 convo. 2. Self-concept measure: participants changed their perceptions of themselves (no quantitative data provided) 3. No results provided	Follow up- no Generalization-yes Social validity- no Inter observer agreement-no Treatment fidelity-no Certainty: suggestive.
Palmen et al (2008) Netherlands	9 17-25 7 Males ASD HF Mean IQ- 106 3 groups of 3	Training session consisted of three parts: (1) introduction, (2) evaluation of simulated conversations, and (3) role-play. Weekly session with personal coach, for tutorial conversations, for opportunities to ask for help and for generalisation of skills 7 weeks (1 hour)	Enhancement of social interaction and communication Dependent variables: % of correct questions during conversation	Design: Non concurrent multiple baseline design across three groups Outcome: Positive Positive: correct questions improved for all participants following intervention, a significant increase was found for group.	Follow up: yes; Generalization: yes; Social validity: yes Inter observer agreement: yes Treatment fidelity: not reported, however, trainer used a flowchart of the procedure to control for variations in implementation Certainty: conclusive

Management of emotional distress/ enhancement of quality of life					
Panke et al (2013) Sweden	28 21 Males 13-21	Acceptance and commitment therapy-based skills training group. 6 weeks (two 40-min sessions per week)	Managing emotional distress and enhancing quality of life	Design: Feasibility study A quasi-experimental pilot study Outcome: Mixed	Follow up- yes Generalization-yes Social validity-yes Inter observer agreement-no Treatment fidelity-no Certainty: suggestive
	(15 intervention 13- WL) 28- HF IQ- not reported	Plus 6 to 12 mins of daily mindfulness exercises in the classroom.	<ol style="list-style-type: none"> 1. Stress Survey Schedule (teacher- and self-ratings), 2. Strengths and Difficulties Questionnaires (SDQ; teacher- and self-ratings), 3. Beck Youth Inventories (BYIs; self-ratings) 	<p>Reduction in self-reported stress but not teacher reported stress.</p> <p>A decrease in self- and teacher-reported hyperactivity and emotional symptoms, self-reported pro-social behaviour was increased.</p> <p>Non sig on some aspects of measures.</p>	
Spek et al (2013)	18-65 41	Mindfulness based cognitive therapy 9 weekly (2.5 hours) 40-60 minute practice daily	Managing emotional distress and enhancing quality of life	Design: RCT Outcome: Positive	Follow up-no Generalization-homework tasks Social validity-no Inter observer agreement-no Treatment fidelity-no Certainty: preponderant
	21- control group (TAU) 20- experimental group 27 male 14 female 21 autism 11 Asperger's 9 PDD-NOS IQ score not available, inclusion criteria stated IQ of 85 or higher		Self-report <ol style="list-style-type: none"> 1. The Symptom Checklist-90-revised 2. The Rumination-Reflection Questionnaire 3. The Dutch Global Mood Scale 	All sig	

Enhancement of social skills and management of emotional distress combined					
Fullerton and Coyne (1999)	23 13 males 16-27 (HFA/ASD) No IQ reported	Communication program unit in Social Skills Group 10 weeks (2-3 hours weekly)	Managing emotional distress and enhancing quality of life and Enhancement of social interaction and communication Participant and parent interviews	Design: Pre-Post Outcome: Positive 2 speech-language therapists identified post responses adequately on dyadic scenario for all participants.	Follow up: yes but not reported Generalization: yes; Social validity: no Inter observer agreement- yes Treatment fidelity-no Certainty: suggestive
Hillier et al (2011) USA	49 18-28 42 Males Asperger's- 42 HFA- 6 PDD-NOS-1 Mean IQ - 99.9 9 groups	Aspirations group intervention 8 weeks 1h	Managing emotional distress and enhancing quality of life Self-report: 1- Beck Depression Inventory (BDI) 2- State-trait anxiety Inventory (STAI) 3- Index of Peer relations (IPR)	Design: Pre-post Outcome: Mixed BDI- sig STAI- sig IPR- non sig Small effect sizes	Follow up: no Generalization: no Social validity: no Inter observer agreement: no Treatment fidelity: no Certainty: suggestive
Mitchell et al (2010) Canada	3 1 Male (15-19) 2-ASD 1-HF No IQ reported	The social skills curriculum was adapted from "Navigating the Social World" (McAfee, 2002) <i>Group Parent Training</i> 12 weeks (2 hours)	Enhancement of social interaction and communication 1. Social Skills Rating System- parent and self (SSRS) 2. Quality of life – self (QOL)	Design: Single-case multiple baseline designs Outcome: Mixed SRRS self- sig SRRS parent- all sig except for one participant. QOL- sig	Follow up- yes Generalization: yes Social validity- yes Inter observer agreement- yes Treatment fidelity- no Certainty: suggestive
Tse et al (2007) Canada	44 28 Males 13-18 AS/HFA (no further info) IQ not reported, all had adequate language skills.	The group curriculum combined psychoeducational and experiential methods of teaching social skills, with emphasis on learning through role play. 12 weeks. (1.5 hours)	Enhancement of social interaction and communication and Managing emotional distress Informant measures 1- The Social Responsiveness Scale (SRS), 2- The Aberrant Behavior Checklist (ABC), 3- The Nisonger Child Behavior Rating Form (N-CBRF).	Design: Pre-Post Outcome: Positive SRS- sig ABC-sig N-CBRF- sig	Follow up- no Generalization-no Social validity-yes Inter observer agreement- no Treatment fidelity- no Certainty: suggestive

N: Total number of participants in study/number of participants included in review; PDD-NOS: pervasive developmental disorder not otherwise specified; NR: not reported; FU: follow-up; Gen: generalization; SV:

social validity; IOA: inter observer agreement; TF: treatment fidelity; AS: Asperger syndrome; PND: percentage non-overlapping data; HFA: high-functioning autism; ASD: autism spectrum disorder

Section 3: Research Paper

**A separate togetherness: participants' and facilitators' experiences of a
social skills intervention for young adults with ASD**

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Appendix B- Autism Research and Treatment: Guidelines for authors

Author Guidelines

Submission

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Units of measurement should be presented simply and concisely using System International (SI) units.

Title and Authorship Information

The following information should be included

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- Full author names
- Full institutional mailing addresses
- Email addresses

Abstract

The manuscript should contain an abstract. The abstract should be self-contained and citation-free and should not exceed 200 words.

Introduction

This section should be succinct, with no subheadings.

Materials and Methods

This part should contain sufficient detail so that all procedures can be repeated. It can be divided into subsections if several methods are described.

Results and Discussion

This section may each be divided by subheadings or may be combined.

References

Authors are responsible for ensuring that the information in each reference is complete and accurate. All references must be numbered consecutively and citations of references in text should be identified using numbers in square brackets (e.g., “as discussed by Smith [9]”; “as discussed elsewhere [9, 10]”). All references should be cited within the text; otherwise, these references will be automatically removed.

Preparation of Figures

Upon submission of an article, authors are supposed to include all figures and tables in the PDF file of the manuscript. Figures and tables should not be submitted in separate files. If the article is accepted, authors will be asked to provide the source files of the figures. Each figure should be supplied in a separate electronic file. All figures should be cited in the paper in a consecutive order. Figures should be supplied in either vector art formats (Illustrator, EPS, WMF, FreeHand, CorelDraw, PowerPoint, Excel, etc.) or bitmap formats (Photoshop, TIFF, GIF, JPEG, etc.). Bitmap images should be of 300

dpi resolution at least unless the resolution is intentionally set to a lower level for scientific reasons. If a bitmap image has labels, the image and labels should be embedded in separate layers.

Preparation of Tables

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Abstract

Social skills deficits are a central feature of autism spectrum disorders (ASDs). Social skills interventions aim to increase the ability to perform key social behaviours that are important in achieving success in social situations. This study describes a thematic analysis of participants with an ASD ($n=4$) and facilitators' ($n=2$) experiences of a social skills intervention. Richly detailed accounts from participants and facilitators described a broad range of individual and group based processes. An overarching concept of *separate togetherness* was identified in the data, which refers to the shared but individual learning experience within and between the participants and the facilitators. There were many similarities (e.g. preconceptions about the intervention and intervention outcomes) and a few differences between their accounts. The disparities between the two groups highlighted that participants with ASDs wanted to be 'pushed out of their comfort zone', which the facilitators were not aware of. This demonstrates the value and importance of including both sets of perspectives in intervention research. Improving social skills is a particularly crucial and challenging area that must be addressed to facilitate those with ASDs in adulthood, and future research is needed.

Autism spectrum disorders (ASDs), Asperger's Syndrome (AS), High Functioning Autism (HFA), and Pervasive Developmental Disorders— Not Otherwise Specified (PDD-NOS) are developmental disorders characterized by three core features: impairments in social interaction; impairments in communication; and restricted, repetitive, and stereotyped patterns of behaviour, interests and activities [1]. The presentation of these impairments is variable in range and severity, and often changes with the acquisition of other developmental skills.

Unlike classic autism, AS/HFA is not associated with a delay in cognitive or language development [1] however, despite this, research shows that these individuals consistently underperform across basic life domains [2, 3]. Howlin and Moss [4] reviewed adulthood outcome studies in ASDs and concluded that many adults with ASDs, including those with AS/HFA, experience difficulties or disadvantages in a range of areas, including employment, social relationships, health and quality of life. Whilst acknowledging the cognitive and linguistic differences between individuals with ASDs and AS/HFA, the term ASDs will be used to represent individuals with ASDs, HFA, AS, and PDD-NOS throughout this paper.

Socialisation difficulties among individuals with ASDs can include impairments in the use of non-verbal behaviours (e.g., gestures, eye contact), difficulty establishing and maintaining peer relationships, problems with understanding the subtleties of social situations, inappropriate social or emotional responses, and a general lack of social or emotional reciprocity [1, 5]. Many individuals with ASDs are also “*acutely aware of their difficulties with social communication and integration*” [5, p. 97] and report experiencing more loneliness and social isolation than their typically developing peers [6]. This in turn may contribute to the development of secondary mood and anxiety problems, which are also prevalent in this population [7]. Individuals with ASDs often desire social contact with peers,

yet have fewer social relationships and friendships due to limited social-emotional understanding [6]. These findings suggest the need for provision of social skills instruction to improve the social relationships and psychological wellbeing of this potentially vulnerable population.

Social skills interventions aim to teach the social interaction skills necessary to build and foster relationships with others. Tasks often include starting and maintaining conversation, empathy, self-regulation, and conflict management [8, 9]. There is currently no consensus regarding the most appropriate or effective structure or content of social skills groups for adults with ASDs, which has resulted in multiple variations of social skills interventions in the literature (e.g. group, individual, parent/carer assisted etc.).

Whilst there is empirical support for the effectiveness of group social skills interventions for adolescents with ASDs (e.g. [6, 10, 11, 12, 13]) the literature focusing on adults is relatively under researched. Previous studies for an adult population have investigated the Aspirations group intervention [14] the UCLA PEERS for Young Adults Program [15], Social Cognition and Interaction Training [16] amongst other bespoke social skills interventions [17, 18]. The interventions mentioned have some shared commonalities, however the differences between them makes it difficult to work out what makes an effective social skills group intervention. The studies mentioned above reported significantly improved results in some but not all areas of social interaction.

The National Autistic Society (NAS) recently developed a social skills intervention called Socialeyes which was uniquely developed as “*a social skills learning resource developed with, and for, people with autism and Asperger syndrome*” [19]. The Socialeyes intervention reports to be ‘ASD friendly’ due to its predictable, repetitive, structured, and visual qualities. The intervention uses teaching methods such as video modelling, live modelling by

facilitators, role-play, and reflective discussion. Socialeyes training is readily available from the NAS and is reported to be used by clinicians across the UK. To date, no research has formally examined the effectiveness of the Socialeyes intervention. This study is part of a wider feasibility project. The current study presents the qualitative data that was collected post- intervention.

There is a dearth of qualitative research exploring adults' experiences of attending a social skills group intervention. Fullerton and Coyne [17] however, explored the impact of a group based social skills program in 23 young adults with ASDs. The majority of participants reported that the main benefits of the intervention was learning more about ASDs, increasing self-awareness, and having the opportunity to share experiences and learn from each other.

Previous group intervention literature has suggested the use of multi-perspectives as the most effective way to capture a comprehensive and balanced assessment of the effectiveness of an intervention [20]. Researchers have shown the value of a multi-perspective qualitative approach in diverse clinical areas such as the couple's experience of breast cancer recurrence [21] and the complex clinician-patient interactions around requests for physician-assisted suicide [22].

No identified studies have explored qualitative multi-perspective accounts of a social skills intervention for individuals with ASDs. The aim of the study is to investigate participants' experiences of taking part in a Socialeyes intervention and the facilitators' experiences of running the intervention.

Method

This study was part of a larger feasibility study that explored the effectiveness of Socialeyes for adults with ASDs. The current study presents the qualitative data that was collected post-intervention.

Participants

Four individuals with ASDs (three male, one female), aged between 19 and 25 years old took part. All participants were university students, three lived in university accommodation, and one lived in their family home. They all had a diagnosis of an ASD, as confirmed by participants' original ASD assessment reports (see Table 1). One participant could not locate her assessment report; however she provided a GP report as evidence of her diagnosis.

The two group facilitators were female and employed by the University. Both had experience of working with people with ASDs. The two facilitators attended the 2-day NAS Socialeyes facilitator training, which is highest level of training offered by the NAS for Socialeyes.

<Insert Table 1>

Procedure

Ethical approval was obtained from the University of Bangor, School of Psychology and the NHS ethics committee (see Section 5 Ethics Appendices). The facilitator from the University Student Support Service identified potential participants to take part in the study. Inclusion criteria for participation in this study included:

- Age range - 16 to 30 years old.

- Documented evidence of a diagnosis of an ASD from a health professional or allied health professional.
- Have age appropriate language skills.
- Currently receiving support from the University's Student Support Service.

Individuals who met the inclusion criteria and were currently receiving support from the service were sent information about the study. Participants who were interested in taking part were invited to an initial appointment by the facilitator. They were given a study pack comprising a participant invitation letter and consent form (Section 5 Ethics Appendices). Once written consent was obtained, participant's contact details were forwarded to the research team who arranged a baseline assessment. The participants attended a 10-week Socialeyes group. The participants and facilitators were invited to participate in an interview at the University Student Support Service offices following the conclusion of the intervention. All interviews were audiotaped and transcribed verbatim. The participants were also asked to provide a copy of their original ASD diagnosis assessment report, and they returned these to the research team by post.

Data collection

Participants A semi-structured interview schedule was developed for the study to examine participants' experiences of attending the Socialeyes group (Appendix C).

Interviews lasted between 13 and 45 minutes.

Facilitators A semi-structured interview schedule was developed to explore the facilitator's experiences of running a Socialeyes group (Appendix D). Interviews lasted between 40 and 47 minutes.

Description of the Socialeyes intervention

a) Socialeyes program Socialeyes does not ask people with ASDs to change 'inappropriate' social behaviour, or to acquire social skills by copying the 'typical' behaviour of others. Instead, it gives people the option of learning social interaction skills or alternative social strategies. Socialeyes focuses on eight social skills that people with ASDs can have difficulty with: a) starting a conversation, b) eye contact, c) personal space, d) taking turns in a conversation, e) keeping on topic, f) talking about interests, g) sensitive topics, and h) ending a conversation. The Socialeyes program offers a structure, whilst encouraging a degree of flexibility in terms of timing, duration of sessions, and use of resources. Further information about the intervention and the worksheets used within Socialeyes can be seen in Appendix E and F.

b) Socialeyes group sessions. The participants attended a weekly Socialeyes group, led by the facilitators. The first three sessions were 60 minutes in duration, but this was expanded to 90 minutes following feedback from participants. The sessions were held at the university student support department as this was a familiar venue for the participants. The participants were invited to bring their student mentors to the sessions if they wished to do so. Due to time constraints, all topics except 'ending a conversation' were covered and 'sensitive topics' were only briefly discussed.

Data analysis

The data was analyzed using Thematic Analysis 'TA' [23]. TA examines and records patterns (or "themes") within data. Braun and Clarke [23] state that it provides a flexible and useful research tool, which can provide a rich and detailed account of qualitative data. TA has been the chosen methodology for previous studies which have investigated both

participants' and facilitators' accounts of a group intervention [24, 25] and thus was deemed most suitable for this study. TA is useful when comparing two groups, due to its flexibility, inductive approach, and strength in highlighting similarities and differences across the data set.

The process of analysis

The analysis was conducted according to Braun and Clarke's [23] TA guidelines. The steps reported below were completed for each participant's transcript. Each transcript was read several times, line by line, with the first author noting down particular points of interest and notes in the margins of the transcript (See General Appendix 1 for an extract of this stage of the analysis). The transcripts were read again and initial notes and ideas were transformed into initial codes. These initial codes were placed into potential themes, with one theme table produced per participant (see General Appendix 2 for an example of this stage of the analysis).

At this stage two main theme tables (one which collated the four participant interviews and one for the two facilitator interviews) were generated which included specific and concise themes and the supporting extracts of data for both groups. Two diagrammatic illustrations of the themes (one for the participants and one for the facilitators) were generated (see General Appendix 3). Following analysis of the two main theme tables and the diagrammatic illustrations of the themes the first author, in collaboration with the third (for triangulation purposes) identified eight overarching themes, which encompassed both the participant and the facilitator interviews. The facilitators' table was merged with the participants' table, and any themes that did not overlap were placed at the bottom of the table. For example, both the participants and the facilitators spoke about preconceptions about the group, therefore the participants and the facilitators quotes were placed together in the table under the heading

‘preconceptions’ (see General Appendix 4 for an example of how the theme tables were combined). From this point onwards, the participants’ and the facilitators’ data was analysed as one whole data set.

The next steps involved analyzing and exploring connections between concepts and documenting key themes. Further analysis was undertaken to refine the specifics of each theme, and to generate clear definitions and names for each theme. Finally, rich data extracts were selected to illustrate the resulting themes. Analysis and theme development continued throughout the write up of the results. As is usual during TA, the list of superordinate themes and sub-themes changed throughout the analysis and write-up, until the final two superordinate themes and subthemes were identified.

In order to increase the credibility of the research, respondent validation, or “member checking,” was also undertaken with one facilitator as recommended by Guba and Lincoln [26]. It consisted of taking data and interpretations back to the facilitator so that she could confirm the credibility of the information and narrative account, ensuring that it reflected her experience. To enhance the reliability and validity of the TA analysis, a process of triangulation [27] was undertaken with the third author. This involved transcripts being read separately and themes checked for relevance, with alterations made when required.

Results

An overarching concept of a *separate togetherness* was identified in the data, which refers to the shared but individual learning experience that occurred both within and between the participants and the facilitators. Two superordinate themes were identified; *Individual journeys* and *Group based processes*. The first superordinate theme, *Individual journeys*, comprised two subordinate themes: 1.1) *Taking the leap* and 1.2) *Intervention outcomes for the participants* and refers to the individual learning of each person during Socialeyes. The

second superordinate theme, *Group based processes*, included three subordinate themes: 2.1) *Sense of togetherness*, 2.2) “*Going outside my comfort zone*” and 2.3) *Increasing understanding about ASDs*. Themes are detailed in Table 2.

<Insert Table 2>

Superordinate theme 1. Individual journeys

1.1. Taking the leap. The participants and facilitators spoke about their preconceptions about attending or running the group, which included both positive and negative expectations. One participant said:

“It was better than I expected... I thought it was going to be a bit lame and that nobody was going to say anything... Because what exactly do you hope to get out of a bunch of socially awkward people when you throw them in a room together and tell them to socialise?”(Jac)

Jac’s words highlight his preconceptions about the social abilities of the other individuals attending. The quote also suggests that Jac did not have a clear idea of the purpose of Socialeyes, and seemed to misinterpret or exaggerate what he thought would be asked of the group (i.e. placed in a room and told to socialise).

Barry and Twm also spoke about their worries about attending the Socialeyes group. Barry’s quote highlights that he wanted to contribute to the group but anticipated he would find this social encounter difficult, and Twm was worried about the size of the group.

“[I was worried about] meeting new people...and trying to contribute to the group.” (Barry)

“I was expecting eight people so when I saw four people I felt a bit more confident, because large groups I’m not that keen on.” (Twm)

In contrast, Sophie seemed to have an open-minded approach with few expectations.

Sophie’s words suggest that she perhaps did not have confidence in the effectiveness of the intervention prior to the group.

“It’s going to sound bad when I say I didn’t have that many expectations...I was more going along for the ‘let’s see what this is’ kind of a thing...I didn’t really have ‘I want to know about this and I’m going to make sure I get it’, it was more just a ‘this is kind of interesting, this could help, let’s see what happens.’”(Sophie)

The four individuals approached the intervention with different preconceptions, which later adjusted as the group progressed. Similarly, both facilitators also had preconceptions prior to starting the group.

“You kind of worry, gosh, you know, are they actually going to talk to each other or is it just going to be a bunch of silence.” (Grace)

“I was quite nervous running that group to start with, just thinking because everybody’s got so many different social difficulties. I was thinking ‘Is this just going to be really painful and difficult?’” (Emily)

The quotes above suggest that the facilitators ‘arrived’ at the intervention with a set of assumptions about the participants, which may be representative of their previous experiences of working with individuals with ASDs.

“I realised I’d been a bit worried about there being a difficult situation. I was worried I think that somebody would get upset or anxious, or into an argument or something in a session, I think that was one of my concerns, and when that didn’t happen that was really positive.” (Emily)

The facilitators had similar worries to Jac in regards to whether the group intervention would be effective, or just be an awkward experience. There seems to be an underlying feeling of dread or perhaps anticipatory guilt in the quote below by Emily. Her words highlight her fear about recruiting participants into an intervention that she hadn’t run before, and didn’t know whether it was going to be effective, and the sense of responsibility that appeared to come with this.

“Because I suppose I had this nagging fear that actually they weren’t going to find it useful.” (Emily)

The facilitators and participants had some similar preconceptions and worries about how the group might work beforehand. In addition, the facilitators also reported concerns about managing the dynamics of the group and the effectiveness of the intervention.

1.2. Intervention outcomes for the participants. All of the participants spoke positively about the intervention and how they had benefitted from attending the group. They spoke about the group increasing their confidence, their self-awareness, and improved their social skills. The facilitators also reported that they observed similar outcomes.

1.2.1. Increase in confidence. The participants described how they increased in self-confidence as a result of attending the group.

“I learnt that I could be a lot more confident around others...Two of the people that sit by me in lectures, I never actually spoke to them last year, [but after the group] I’ve been talking to them...I’m more confident and I’ve used it with my course mates.” (Twm)

Jac also reported that he felt more confident and less worried about interacting with others following the group.

“I’m not scared of people anymore...maybe less anxious now. It’s made it easier for me... where someone has come to interact with me, but has not yet been able to make it so that I feel comfortable going to interact with someone else... If somebody tries to interact with me I’m fine now, and I would credit the group as helping.”(Jac)

The increase in participants’ confidence was corroborated by the facilitators who described how they noticed an improvement in the participants’ confidence levels as the group progressed. The quote below describes how Grace found this especially rewarding to see, and indicates that the facilitators were very aware of the individual journeys of the participants within the group, the ‘separate togetherness’. All of the participants were on individual journeys but continued to be connected as part of the wider group.

“To see certain people grow in confidence was just so rewarding, or just someone speaking for the first time. One of the people wrote [in the first Socialeyes session], ‘I’m really anxious that I won’t be able to contribute anything’. And he didn’t speak for maybe the first couple of sessions, and then he started adding in sentences or he’d just say one or two things.” (Grace)

1.2.2. Increase in self-awareness. The participants spoke about how the group had helped them develop self-awareness and insight into their social difficulties, some of which were previously unknown to them.

“I really liked the real people [adults with ASDs on the video clips] talking about their experiences...I thought personal space isn’t really that much of an issue for me...then the person [on the video] said something and I was like ‘Oh, actually yeah, I agree, I do that’, and then they said something else and I was like ‘Oh yeah, agree with that as well’. It’s more I know myself that is why it’s helped me. Like, because before I wouldn’t really think about it and now it’s kind of more conscious.”(Sophie)

The Socialeyes group dispelled some of the confusion around social interaction and made it appear much more accessible and attainable than one participant had previously believed. Jac’s words highlight that he looked at social interaction in a systematising way, and highlights that social skills was not instinctive for him but something that needed to be methodically learnt, he also realised some of his difficulties with socialising were shared by people without ASDs too.

“Being forced to look at social interaction...I’ve looked at myself, I’ve looked at other people with the same problems, or similar problems, and I’ve looked at people without these problems, and we’re more similar than (laughs) dissimilar... I’ve found out through this that it’s easier than our brains make us think... It’s sort of like it’s been broken down and now I can look at it properly and see what makes the interaction the interaction.”(Jac)

1.2.3. Improvement in social skills. The participants reported specific personal improvements in their social skills following the group.

“I can talk to people better now....and I’m visiting people and I do more now.....I learned to talk to people a bit better... I think carrying on a conversation is a bit better now.” (Barry)

Barry’s use of “*I think*” and “*a bit better*” however continues to suggest an inner narrative of insecurity, lack of confidence, and trepidation in his social skills. Similarly Sophie spoke about improvements in her social skills and how she had incorporated what she learnt about conversations in the group into her everyday life.

“I listen more to people and kind of not be as rude as I used to be.... I’ve taken on board quite a lot of what the modules have been saying... Like starting a conversation, and knowing how long to talk, and allowing other people to talk and stuff....I prompt myself more...” (Sophie)

Sophie also spoke about how the group helped her to tailor her interaction style according to the situation and helped her adopt a more flexible approach to social interaction. This categorising process of systematically adopting different styles of interaction for different situations appeared to fit in well with Sophie’s style of learning. She described how socialising continued to be an effortful and active process, as opposed to being something intuitive.

“It’s made me think a lot about myself in various situations. So like I always I kind of categorise everything, so it helped me categorise how I behave. So that it kind of helped me like balance out the different rules of each social setting I

guess...Like instead of just using one rule for every situation, which is what I'd usually do."(Sophie)

Twm also described a significant change in his social activity, he reported that he made around 30 friends in a short amount of time; however it is unclear from the quote how Twm defines a friend, and what the nature of these friendships were.

"It [the group] changed how I socialise.....Last year I never used to actually leave my room unless it was lectures or shopping, but then I've ended up being one of the organisers of film night... I've actually made about 30 friends after the group...I've started going to [xxx] society, I joined last year but didn't go, but I have more confidence this year to go." (Twm)

Generalisation of skills is often a difficulty for people with ASDs. It was therefore noteworthy to hear about how Sophie was actively practicing her skills outside of the group environment. Like Jac, Sophie appeared to have a methodical and systematic style of learning and seemed to make a conscious effort to practice her skills and appeared to be fully invested in applying the skills learned from the intervention.

"I'd go to my friends and practice my skills, and then kind of go away and then like relay it to the group and then get feedback. The homework was quite useful as well, because I'd try them out in each of my three different categories [with friends, in formal settings, with strangers]."(Sophie)

In contrast, Jac spoke about how he found it difficult to generalise skills learnt to outside of the group.

“Like we got through the how to start a conversation topic...and while I understand now how and why and all that stuff I still don’t do it. We need something to just really encourage us to go out of our comfort zones and interact with strangers.”(Jac)

It seems that although the group helped Jac to understand the individual sections that facilitate social interaction, there were barriers at play (that he did not specify) that stopped him from adopting the steps and generalising the skills learnt to his everyday life. The facilitators also spoke about how the group was effective in teaching social skills but did not help the participants to overcome their personal barriers, such as anxiety, to implement the skills.

“The topics were good, but they were kind of skills building, so people understood that making eye contact was a good thing. So that was understood on an intellectual level, but still people were like ‘Well I can’t do it’ -I don’t enjoy making eye contact’. Then how do you address that underlying anxiety and that wasn’t addressed in Socialeyes. I think people understand things on an intellectual level very clearly, but putting it into practice is something else.”
(Grace)

The quote above highlights the concordance between the facilitator, Grace, and Jac’s views around the difficulty of generalising the skills to outside of the group environment. Grace offers a possible hypothesis as to why this was a significant difficulty for the participants. She described how individuals can learn the required skills however without addressing the underlying anxiety about putting these skills into practice, behavioural change will be limited. The next quote highlights how Grace realised she had overestimated Jac’s social abilities as a result of his intellectual level of understanding.

“Jac, at the end said that he would like to do it all over again but with more time. Which I was surprised at really because he is probably one of the most high functioning people in the group. At the end he said ‘Well, I picked up on it, but I need to apply it’. (Grace)

Some individuals found it difficult to generalise skills learned at Socialeyes to everyday life, and Socialeyes did not address identification of barriers for implementing the skills which can be a key factor when trying to accomplish behavioural change.

Superordinate theme 2. Group based processes

2.1 Sense of togetherness “Everybody in the group is in the same boat”

Despite misgivings before the intervention started, the participants and the facilitators felt the group was a comfortable and safe environment which facilitated a shared learning experience. They spoke about a sense of togetherness within the group that enabled the participants to discuss and share personal experiences.

“In a situation where everybody in the group is feeling exactly the same. Everybody in the group has the same problems. Everybody in the group is in the same boat. It makes it a lot easier to keep your nerve when... everyone there is feeling just as nervous as you.”(Jac)

The sense of togetherness was supported by Sophie who spoke about the group providing some validation for her experiences. Her words seemed to reflect a sense of realisation that she wasn't alone with her experiences.

“On a personal level, it was just meeting other people with the same condition, that was a good thing, and it made it easier to share my experiences. Quite a few of us shared quite a lot of personal stories.” (Sophie)

This was similar to Twm’s account of the group being a contained and non-threatening environment. The words “*able to not judge me*” suggests that Twm may have had negative experiences in the past of being judged by others.

“Being with people who had similar experiences to what I had in the past was actually helpful ... it was friendly,.... I could speak my own mind... and I was glad that everyone else was able to not judge me.” (Twm)

Both facilitators spoke about the group providing a safe, validating and accepting environment for individuals to share their experiences. Emily highlights the ethos of acceptance within the group and refers to the non-judgmental atmosphere created within the group.

“A lot of it is to do with just giving people that opportunity to be able to talk about how they feel, and how difficult they find these things together, that seemed to be a really valuable thing for them...and I think we created a safe space, which was really good.” (Emily)

Grace described the sense of togetherness as something extremely valuable but also something very difficult to define. Her words highlight her difficulty of defining the spontaneous and unmeasurable processes that occurred within the group.

“I think that’s a really important but un-specifiable thing that people get out of it is this idea of okay, we’re in a group, we’re all feeling the same way, and

drawing that experience out of people...you get this kind of universal experience of 'Oh gosh, yes this is what Asperger's is about,' and something about that's just so valuable." (Grace)

2.2 "Going outside my comfort zone"

There seemed to be an agreement that the group provided a comfortable and safe environment for people to contribute and share experiences. However, two of the participants also stated that although this was useful at the beginning of the group, as the weeks progressed, they described wanting to be challenged more. The quote below by Jac highlights his uncertainty about this and his thought processes around finding his own balance between being supported and challenged.

"I'm not comfortable in groups. But at some point, if we're going through life we're going to have to deal with things sooner or later. There's no point sugar coating it, especially if the entire point of the Socialeyes programme is to make us better socialisers, or at least help us understand it better. We're not going to do that if we aren't thrown into the deep end out of our comfort zone. And I don't like going outside my comfort zone, but I do it sometimes; sometimes I don't, sometimes I run away from going outside my comfort zone."(Jac)

Sophie spoke similarly about the low demands placed on the participants within the group. It appears that Sophie became more confident to challenge herself as she became more comfortable in the group.

"It was all very much up to us what we did, so there wasn't any pressure at all. Maybe on the one hand, I quite liked like that, but it would have been better later

on if they'd gone 'Okay, this is how we're going to do it, today we'll do a discussion, a role play, and then another discussion.' Sophie)

For the first few sessions of Socialeyes a comfortable and low demand environment was needed and appreciated, however as the group progressed; two participants felt that they would have benefited from additional challenges. The quotes highlight the difficulty of managing the individual needs of participants in a group intervention and for facilitators to be aware of the dynamic nature of the group. It suggests that any modifications in pace or intensity needs to be carefully managed in order to maintain the balance between a gentle acceptance of participants' need for security, and the need for going beyond their comfort zones.

The facilitators also spoke about the difficulty of getting the balance between providing a comfortable and non-threatening environment and challenging the participants.

"We didn't give very many demands. I don't think we did 'try' [when participants practice newly learned skills] in the first couple of sessions at all, and then we kind of introduced that a bit more and made those 'try' sessions a bit longer, and allowed them a bit of free chat in the 'try' sessions, which was really great." (Emily)

The quote above highlights the facilitators' efforts to be mindful of the group's needs, and their sensitivity in managing demands placed on the participants meant that they did not place many demands on the group. However, two participants expressed that they were not challenged enough during the latter stages of the group. It therefore appears that the facilitators were not aware of the change in participants' needs during the later stage of the intervention. The participants did not say that they had provided feedback about wanting to

be challenged more to the facilitators. Both the participants and the facilitators discussed the evolving nature of the group, however the participants and the facilitators had different perceptions about the demands and intensity of the intervention. There seemed to be a lack of communication and feedback about the pace and intensity of the intervention which seemed to maintain the dissonance. This further supports the underlying concept of a separate togetherness within the data.

2.3 Increasing knowledge about ASDs

Although not a focus of the interview questions, the facilitators discussed the effects of the group on their own personal and professional development. Both facilitators had worked with individuals with ASDs for many years, however, facilitating the group provided them with additional knowledge and insight about what life is like for individuals.

“I work with lots of students with ASDs, but to actually really hear their stories that are outside of university-related stuff, I learnt more. So it’s that personal sort of insight into things I suppose. I have got knowledge and experience, but I think something about the group interaction has given me an added insight.”(Emily)

Similarly Grace noted that the group made her re-evaluate her previous knowledge about ASDs. She reflected on the individual nature of ASDs and on the most useful way to help the individuals that she worked with.

“Even with the four people we had, they were just all completely different, so it’s made me think a lot more about ASD and how to accommodate different people and how to approach that I think.”(Grace)

For one facilitator, who was also a tutor at the university and knew most of the participants prior to the group, facilitating the Socialeyes group provided the freedom and opportunity to discuss sensitive topics openly with participants that she had found difficult in the past (in her role as tutor). The group also helped her to understand the barriers and difficulties facing individuals with ASDs.

“I found it a good way to get issues out on the table that sometimes you might not feel comfortable about discussing like eye contact, or ending a conversation [in a one to one situation as a tutor]. We’re very much looking at the barriers that somebody meets in the University and what adjustment we need to make. So I suppose it’s just given me more of the human side of things in a way.” (Emily)

Similarly the group appeared to provide an opportunity to openly share information about ASDs, and to help individuals place their difficulties in the context of their diagnosis. Two participants spoke about the benefit of acquiring general knowledge about ASDs from the group. The group appeared to provide belated post diagnostic support for Sophie. Psycho-education about ASDs is not an explicit part of Socialeyes, but naturally arose from the group discussions. Despite the ad-hoc nature of the discussions, learning more about ASDs played a significant role in some participants’ experiences of the group.

“And it also made me question a lot of things, because I only got my diagnosis a few years ago. I hadn’t really had that much information about what Asperger’s is, it was just like okay, you have this, and I kind of had to find out the information myself. And doing the course has kind of made me learn a bit more, and made me feel a bit better about why I do things, and then how to cope with things.” (Sophie)

Twm appeared to value hearing from other people with ASDs about their difficulties and how to manage them. His words suggest that he seemed surprised that anyone could have a diagnosis of an ASD irrelevant of age, religions, professions or gender (as there were a range of people on the Socialeyes DVD clips) which seemed to provide comfort that he wasn't alone in having a diagnosis.

“Good to hear about other people’s experiences, cause we’re only one type of person, we’re just students, and you could hear from people from many different professions, ages, religions, genders, ...you could hear, like no matter who you are this could affect you and this is how it could affect you, and also it gave you some ideas how to improve, how to go about certain actions.” (Twm)

Discussion

The current study was designed to investigate participants’ and facilitators’ experiences of attending and facilitating the Socialeyes intervention. Richly detailed accounts from participants and facilitators described a broad range of individual and group based processes. The inclusion of the facilitators distinguishes our study from previous studies and enabled a more nuanced insight into how the group functioned, by combining the experience of both participating and facilitating a social skills group intervention.

An overarching concept of separate togetherness was identified in the data, which refers to the shared but individual learning experience within and between the participants and the facilitators. The concept of separate togetherness also refers to the areas of disparity and consistency between the participants and the facilitators’ accounts. The accounts were mostly consistent; however, there were some areas of divergence which highlighted the value of exploring multiple perspectives within intervention research.

Both the participants and the facilitators described the group as an overall positive experience and described an increase in participants' confidence, self-awareness, and social skills following the intervention. Participants' high attendance rates also suggest that they found the intervention valuable and enjoyable. The semi-structured interview technique also enabled the identification of unexpected benefits of the intervention. These included having the opportunity to share experiences and learn from each other alongside gaining a deeper understanding of ASDs. The current results were similar to findings in a qualitative study by Fullerton and Coyne [17] whose participants also reported that a significant benefit of the social skills group was meeting other individuals with an ASD and having the opportunity to learn from others who could relate to them.

Despite a reported increase in understanding of social skills, some participants had difficulty generalising those skills into their everyday life. Extensive evidence demonstrates that generalisation of skills often forms the most significant challenge for individuals with ASDs [28]. This was highlighted in the current study with some participants reporting that they were able to successfully generalise skills learnt to their everyday life, and others finding this more difficult. The lack of reported generalisation of skills may be explained by many different factors. Previous research has stated that social skills must be learned in the context of social situations and in natural settings [28]. Although a group intervention provides opportunities for individuals to practice skills with one another, the classroom setting may not be generalisable to 'real life' situations for some participants.

Creating opportunities for individuals to practice their skills outside of the group (e.g. in a café, in a social club etc.) whilst being supported by facilitators and other participants may be an important consideration for future social skills interventions. The participants would therefore be able to practice their skills in real life situations but with added support and

scaffolding in place. This may also address some of the potential generalisation barriers such as having limited opportunities to practice skills due to a restricted social circle, financial difficulties or practical reasons such as transportation issues.

One of the participants and a facilitator identified that there were personal or emotional barriers in place that made it difficult to use the skills learnt outside of the group setting. Although the participant did not articulate what the barrier was, a facilitator suggested it may have been anxiety. Few previous studies have examined the broader outcomes for social skills interventions, such as a reduction in anxiety and depression, despite the prevalence of these comorbid conditions among those with ASDs. Hillier et al. [14] reported significantly reduced rates of depression and anxiety in adolescents and adults with ASDs following a social and vocational skills intervention program. Certainly social skills, relationships with peers, and anxiety seem closely intertwined therefore addressing anxiety and depression within a social skills group intervention may improve the application of social skills and other ASDs symptomology [29, 30].

The theme of “*Going outside my comfort zone*” was a theme that identified discrepancies between the participants’ and the facilitators’ reports and highlighted the value of exploring both perspectives. Some of the participants reported that they felt a need to be challenged more within the group. The facilitators felt demands were carefully managed, and were tentative about placing more demands on the participants. The disparity between participants’ and facilitators’ accounts highlights the difficulty of assessing the appropriate pace and intensity of a group intervention. A safe, supportive, and validating environment seems fundamental in a group intervention, however the participants’ accounts suggest that support alone is not always sufficient for change.

Guidelines for interventions for individuals with ASDs usually consist of lowering demands and paying careful consideration to the intensity and pace of the intervention in order to regulate anxiety levels. Although this is extremely important, in some cases there is a danger that doing this may reinforce a pattern of social avoidance and thus de-skill individuals. The balance between support and challenge needs to be assessed regularly in order to encourage individuals to step out of their comfort zone in a safe manner. Interventions may therefore need to provide regular opportunities for participants to feedback. This could be in the form of an informal group discussion or in a written form if participants preferred. Another suggestion would be to undertake a brief chat with every participant individually halfway through the intervention to assess each individual's progress and goals for the group. The sense of togetherness created within the group encouraged an ethos of belonging and safety and therefore seems to have provided the optimal environment in which social risks could be taken more easily.

Limitations and future studies

This study was limited by the initial response rate to participate in the Socialeyes intervention. A larger study could have included more participants to provide a broader representation of experiences of Socialeyes. However, the aim of this study was to represent the particular experiences of those who took part in the study, rather than generalise across a larger group. One participant interview was considerably shorter, and the participant appeared to find the interview uncomfortable. It is important that research is made as accessible as possible for all participants. Therefore, future qualitative research needs to address these issues by having an alternative structured interview format if needed, for example a written interview online, or in a way that that feels more comfortable for the participant.

Future researchers could consider a longer follow-up period to see if participants' experiences, social networks and life outlooks change with time and whether they continued to utilise the skills learnt in the group. It may also be interesting to explore the benefit of a social skills group with the addition of an anxiety management component.

Conclusion

The Socialeyes intervention seemed to be a positive experience for both the participants and the facilitators, and there were more consistencies than inconsistencies in their accounts. The disparities between the two groups highlight the value and importance of including both sets of perspectives in intervention research. Aside from topics covered in the intervention, the experience of being accepted into a group, meeting others with ASDs and having the opportunity to discuss challenging interpersonal issues seemed to have a positive impact on the group members and the facilitators. Few services are available to individuals on the autism spectrum once adulthood is reached. Improving social skills is a particularly crucial and challenging area that must be addressed if success and independence are to be achieved.

References

1. American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington, VA: American Psychiatric Publishing.
2. Cederlund, M., Hagberg, B., Billstedt, E., Gillberg, I. C., & Gillberg, C. (2008). Asperger syndrome and autism: a comparative longitudinal follow-up study more than 5 years after original diagnosis. *Journal of Autism and Developmental Disorders, 38*(1), 72-85.
3. Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212-229.
4. Howlin, P., & Moss, P. (2012). In Review-Adults with autism spectrum disorders. *Canadian Journal of Psychiatry, 57*(5), 275.
5. Attwood, T. (2000). Strategies for improving the social integration of children with Asperger syndrome. *Autism, 4*(1), 85-100.
6. Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development, 71*(2), 447-456.
7. Myles, B. S. (2003). *Social Skills Training for Children and Adolescents With: Asperger Syndrome and Social Communication Problems*. Autism Asperger Publishing Company.
8. Baker, J. (2003). *Social skills training for children and adolescents with Asperger Syndrome and social-communication problems*. Shawnee Mission, KS: Autism Asperger Publishing Company.
9. Bareket, R. (2006). *Playing it right! social skills activities for parents and teachers of young children with Autism Spectrum Disorders, including Asperger Syndrome and Autism*. Shawnee Mission, KS: Autism Asperger Publishing Company.
10. Barry, T. D., Klinger, L. G., Lee, J. M., Palardy, N., Gilmore, T., & Bodin, S. D. (2003). Examining the effectiveness of an outpatient clinic-based social skills group for high-functioning children with autism. *Journal of Autism and Developmental Disorders, 33*, 685–701.
11. White, S. W., Keonig, K., & Scahill, L. (2007). Social skills development in children with autism spectrum disorders: A review of the intervention research. *Journal of Autism and Developmental Disorders, 37*(10), 1858-1868.
12. Beaumont, R., & Sofronoff, K. (2008). A multi-component social skills intervention for children with Asperger syndrome: The Junior Detective Training Program. *Journal of Child Psychology and Psychiatry, 49*(7), 743-753.

13. MacMahon, R. J. (2004, May). The Fast Track Project. In *Invited address given at the meeting of the NIH Working Group on Methodological Challenges in Autism Treatment Research, Sacramento, CA* (Vol. 6).
14. Hillier, A. J., Fish, T., Siegel, J. H., & Beversdorf, D. Q. (2011). Social and vocational skills training reduces self-reported anxiety and depression among young adults on the autism spectrum. *Journal of Developmental and Physical Disabilities, 23*(3), 267-276.
15. Gantman, A., Kapp, S. K., Orenski, K., & Laugeson, E. A. (2012). Social skills training for young adults with high-functioning autism spectrum disorders: A randomized controlled pilot study. *Journal of Autism and Developmental Disorders, 42*(6), 1094-1103.
16. Turner-Brown, L. M., Perry, T. D., Dichter, G. S., Bodfish, J. W., & Penn, D. L. (2008). Brief report: Feasibility of social cognition and interaction training for adults with high functioning autism. *Journal of Autism and Developmental Disorders, 38*(9), 1777-1784.
17. Fullerton, A., & Coyne, P. (1999). Developing skills and concepts for self-determination in young adults with autism. *Focus on Autism and Other Developmental Disabilities, 14*(1), 42-52.
18. Howlin, P., & Yates, P. (1999). The potential effectiveness of social skills groups for adults with autism. *Autism, 3*(3), 299-307.
19. National Autistic Society. (2010). *Socialeyes*
20. Macintosh, K., & Dissanayake, C. (2006). Social skills and problem behaviours in school aged children with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders, 36*(8), 1065-1076.
21. Lewis, F. M., & Deal, L. W. (1995). Balancing our lives: a study of the married couple's experience with breast cancer recurrence. *Oncology Nursing Forum, 22*(6), 943-953.
22. Back, A.L., Starks, H., Hsu, C., et al. (2002) Clinician patient interactions about requests for physician assisted suicide: a patient and family view. *Archives of Internal Medicine, 162*:1257-1265.
23. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

24. Spector, A., Gardner, C., & Orrell, M. (2011). The impact of Cognitive Stimulation Therapy groups on people with dementia: views from participants, their carers and group facilitators. *Aging & Mental Health, 15*(8), 945-949.
25. Silvergleid, C. S., & Mankowski, E. S. (2006). How Batterer Intervention Programs Work Participant and Facilitator Accounts of Processes of Change. *Journal of Interpersonal Violence, 21*(1), 139-159.
26. Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of Qualitative Research, 2*, 163-194.
27. Banik, B. J. (1993). Applying triangulation in nursing research. *Applied Nursing Research, 6*(1), 47-
28. Bellini, S., Peters, J.K., Benner, L., & Hopf, A. (2007) A meta-analysis of school based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education, 28*(3), 153-162.
29. Kelly, A.B.; Garnett, M.S.; Attwood, T. & Peterson, C. (2008). Autism Spectrum Symptomatology in Children: The Impact of Family and Peer Relationships. *Journal of Abnormal Child Psychology, 36*,1069-1081.
30. Brereton, A. V., Tonge, B. J., & Einfeld, S. L. (2006). Psychopathology in children and adolescents with autism compared to young people with intellectual disability. *Journal of Autism and Developmental Disorders, 36*, 863–870.

Tables**Table 1: Participants' characteristics**

Participant	Gender	Age	Living situation	Diagnosis and date of diagnosis	Details of assessment and year of assessment	Number of Socialeyes sessions attended
Barry	Male	22	At home, living with parent	AS 1999	Developmental history WISC-R ADOS	10
Jac	Male	25	University accommodation	AS 2010	DISCO WAIS-III BADS	9
Sophie	Female	19	University accommodation	AS 2011	Letter from GP confirming AS diagnosis	10
Twm	Male	20	University accommodation	AS 2013	Developmental history WAIS-III AQ EQ	7

Note: AS- Asperger Syndrome, WISC-R- Wechsler Intelligence Scale for Children – Revised, ADOS- The Autism Diagnostic Observation Schedule, DISCO- The Diagnostic Interview for Social and Communication Disorders, WAIS-III- Wechsler Adult Intelligence Scale® - Third Edition, BADS - Behavioural Assessment of the Dysexecutive Syndrome, AQ- Autism Spectrum Quotient, EQ- Empathy Quotient.

Table 2. Table of superordinate and subordinate themes

Separate togetherness	
1. Individual journeys	1.1. Taking the leap
	1.2. Intervention outcomes for the participants <ul style="list-style-type: none"> 1.2.1. Increase in confidence 1.2.2. Increase in self-awareness 1.2.3. Improvement in social skills
2. Group based processes	2.1. Sense of togetherness <i>“Everybody in the group is in the same boat”</i>
	2.2. “Going outside my comfort zone”
	2.3. Increasing knowledge about ASDs

Appendix C- semi structure interview schedule

Interview Schedule: Participant

Interview Schedule: Participant Post-Programme

1. How did you find attending the Socialeyes group?
 - How did you find the group format?
 - What did you think of the materials used and the way information was presented?
 - How did you find the topics covered, length of each group, length of programme?
 - What were the best bits?
 - What was the worst bit?
 - Would you recommend the group to a friend?
 - How would you change the group to make it better?
2. Has attending the group changed anything for you?
Or how has attending the group influenced how you are with other people?
 - Probe for: Behavioural changes (increase or reduction)
 - Explore: Confidence and comfort in social situations
3. Has attending the group had an impact on your how and how much you socialise?
4. Do you have any goals in respect of your social activities or skills?

General prompts which will be used throughout the interview to explore how individuals are making sense of their experience include:

- Can you tell me a bit more about this?
- How does that make you feel?
- How did you make sense of this?

Appendix D- semi structure interview schedule**Interview Schedule: Facilitator****Interview Schedule: Facilitator Post Programme****Training and materials**

1. How did you find the training, in respect of preparing you to deliver the programme?
2. How did you find the resources (DVD, manual, role play scripts, home practice sheets, feedback forms) in respect of supporting you to deliver the programme?

Recruitment

3. How easy was it to recruit people for the programme?
4. What, if any, problems did you encounter?

Running the group

5. Can you tell me about your experience of running the programme?
6. What issues, if any, did you find in delivering the programme? (prompt for: issues on preparation, timing running the group, issues with participants)
7. How relevant did you feel the topics covered were to your participants?
8. How do you think participants responded to the variety of methods used to explore information (e.g. DVD, group discussion, home practice, information sheets)?
9. Did you apply additional strategies (e.g. use of student mentors; if so why?)
10. How far did you feel you deviated from the activities and approach to delivery specified in the manual?

General comments

11. Would you use the programme again?
12. What improvements would you make to the programme?
13. What advice would you give to a new facilitator about to run their first programme?
14. Do you feel that you have become more comfortable in working with clients with ASD as a result of this experience?
15. Have you observed any evidence that running this programme has had an impact within your institution?
16. Any other comments.....

Appendix E: Further information on Socialeyes intervention

Each of the social interaction skills covered was looked at in detail using the Socialeyes five-step process: What? Why? How? When? Try! The five step process included introducing each social interaction skill, looking at the function behind the skill, the way the skill was used by most people in everyday life. It also consisted of explaining the different ways in which the skill may be used, the consequences of using or not using the skill, and the social exceptions to the general rules of using the skill (e.g. not starting a conversation with someone who's on the phone). The *Try* section focused on summarising the previous four steps and putting the steps into practice. The participants were invited to practice the skill with each other and with the facilitators.

Numerous methods were used to facilitate the five step model. These included scripts of social interactions which contained quotes from other people with ASD about each topic. DVD clips of the social skill being used effectively, modelling through facilitators' role playing, discussion opportunities, and providing opportunities within the sessions for participants to practice the skill.

Following each session, home tasks were introduced; which included practicing a skill or observing other people using certain social skills. Further details of the intervention can be found in the Socialeyes manual (NAS, 2008).

Appendix F: Example of the Socialeyes worksheets

Starting a conversation

Individual social action planner

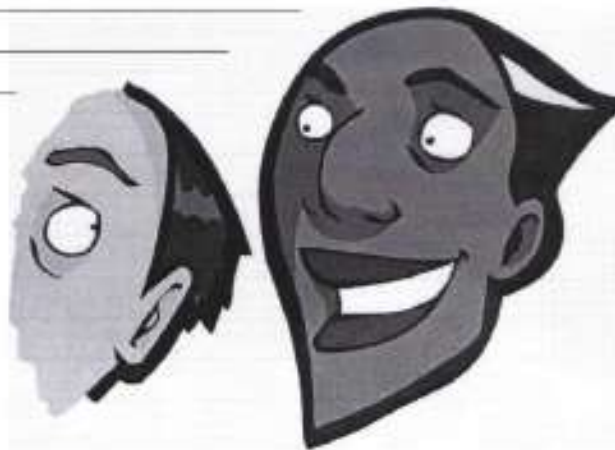
Social strategies

Name: _____

Write a brief description below of the social strategies you will be observing.

Social action record

Make notes below about the social strategies you observed people using. It can be useful to make notes about what the people did with their face and their body; and what sounds they made or what they said.





Starting a conversation

Individual social action planner

Skills in practice

Name: _____

Write a brief description of the social interaction skill or social strategy to be practised.



Make notes about how this social interaction skill or social strategy will be practised.





Social action record

How did you get on with practising this social interaction skill or social strategy in social situations? What went well in any social situation where you practised this social interaction skill or social strategy? What didn't go so well in any social situation where you practised this social interaction skill or social strategy? Make notes below. Use extra paper if you need more space.

Are there any questions you would like answered about how you got on with practising this social interaction skill or social strategy at the next Socialeyes session? Make notes below. You can use extra paper if you need more space.



Starting a conversation

Exceptions worksheet (blank)

Sometimes it's OK for us not to use a social interaction skill or social strategy. This is because there are times when using the social interaction skill or social strategy wouldn't be the most useful thing for us to do. This can be called the 'exception to the rule'.

An exception to the rule for starting a conversation might be if we wanted to talk to someone but they were too busy to talk to us.

So an exception to the rule can often depend on who we are with and where we are.

When we are in a social situation it can be useful to think about who we are with and where we are. It can be useful when we start to interact with others if we stop and think:



- > **Who** are we with? We can think of facts about the person(s) we are with, how this might affect how we decide to behave, and how our behaviour might be seen,
- > **Where** are we? We can think of facts about the situation and the environment we are in, how this might affect how we decide to behave, and how our behaviour might be seen.

Remember, the way we interact with others often depends on **who** we are with and **where** we are.

Sometimes it's OK not to start a conversation. List some examples in the box below.

Who?	Where?	Start a conversation?

Section 4: Contributions to Theory and Clinical Practice

Contributions to theory and clinical practice

Summary of literature review findings

The literature review explored group based psychosocial interventions for adolescents and adults with ASDs. The interventions detailed in the review addressed many of the reported difficulties of ASDs (i.e. social interaction, communication skills, and managing emotional distress). Fifteen studies met the inclusion criteria and almost all studies ($n = 14$) reported improvements in most or all of their targeted outcomes. Our ability to assess the overall benefit of group based psychosocial interventions was limited, due to small sample sizes, variation in study qualities, and the heterogeneous nature of the interventions. Research in this field would benefit from moving in a coherent direction, with researchers developing an intervention and evaluating its effectiveness in large scale controlled studies, rather than numerous researchers publishing pilot or small scale studies on different interventions.

Summary of empirical paper findings

The empirical paper describes a thematic analysis of participants' and facilitators' experiences of attending and facilitating the Socialeyes intervention. Several themes were identified, which are outlined in Table 1. An overarching concept of a *separate togetherness* was identified in the data which refers to the shared but individual learning experience that occurred both within and between the participants and the facilitators. There were more consistencies than inconsistencies in their accounts, and the disparities between the two groups highlighted that participants with ASDs wanted to be 'pushed out of their comfort zone', which the facilitators were not aware of. This demonstrates the value and importance of including both sets of perspectives in intervention research. Few services are available to individuals on the autism spectrum once adulthood is reached. Improving social skills is a

particularly crucial and challenging area that must be addressed to facilitate those with ASDs in adulthood.

Table 1. Table of themes and subthemes.

Separate togetherness	
1. Individual journeys	1.1. Taking the leap
	1.2. Intervention outcomes for the participants <ul style="list-style-type: none"> 1.2.1. Increase in confidence 1.2.2. Increase in self-awareness 1.2.3. Improvement in social skills
2. Group based processes	2.1. Sense of togetherness <i>“Everybody in the group is in the same boat”</i>
	2.2. “Going outside my comfort zone”
	2.3. Increasing knowledge about ASDs

Summary of both papers

The results of the empirical paper and the literature review together suggest that there needs to be a coherent and consistent direction within social skills training for people with ASDs. Both papers highlight the challenge of generalisation of skills when working with an ASD population and the difficulty of addressing the individual needs of participants in a group intervention. The results of the literature review and empirical paper suggest that group based psychosocial interventions show promise, however further, longer-term, exploration is needed in order to consolidate the evidence base.

Research implications

The results of the literature review suggest much work remains to be done in establishing the efficacy of group based psychosocial interventions for adolescents and adults with ASDs. In order to fully explore what type of intervention works best for this population, there needs to be a consistent direction among researchers in this field. The types of intervention implemented within the studies were extremely diverse making it difficult to draw comparisons and fully evaluate the evidence base. The literature review and the empirical paper highlighted several implications for future research. These included the methodology of the studies, diversity of participants' characteristics, outcome measures, accessibility to participate in research, and intervention specific issues. These are discussed further below.

1. Study methodology. The majority of the studies included in the literature review were small scale quasi-experimental studies (for example, pre-/post-treatment comparison, non-randomized group comparison), only three randomised controlled trials 'RCT's' were located. Uncontrolled trials do not permit attribution of observed effects to the intervention (i.e., improvement may be due to the passage of time alone). The majority of the studies included in the literature review reported mostly positive results; however the variation in study methodology made it difficult to compare outcomes across interventions. Although the methodological design of the studies in the literature review didn't seem to affect the outcome of the study (i.e. sometimes small scale uncontrolled studies report better outcomes than controlled RCT studies due to their lack of control procedures), there is a need to conduct high quality, large scale controlled studies in order to have more confidence in the results and consolidate the evidence base.

2. Participant characteristics. The literature review and the empirical paper highlighted the need for more cohesion in relation to participant's characteristics in respect to

age, IQ, language level, diagnosis, and date of assessment in order to be able to compare effects of interventions across studies. More stringent baseline assessments to verify diagnosis would also be useful in future studies as a way to confirm and corroborate diagnoses. Possible baseline measures are the use of comprehensive standardized measures like the Autism Diagnostic Interview—Revised (ADI-R; Rutter et al., 2003) or the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2001).

It is difficult to determine how heterogeneous a sample should be. If inclusion criteria are too stringent, recruitment may be unsuccessful and generalizability may be threatened (Scahill & Lord, 2004). A homogenous population is useful during the initial stages of intervention testing, however once the intervention has undergone sufficient testing, research should focus on determining the effectiveness of an intervention on a wider sample, perhaps by testing on wider age ranges and cognitive functioning levels to increase the generalizability of findings.

3. Outcome measures. 3.1. Lack of validated measures for this population. The progress of intervention research rests on the application of reliable and valid outcome measures that are practical to use and sensitive to change. Unfortunately, few standardized and valid measures are available that are appropriate for use with adults with ASDs (Warren et al., 2011; Scahill & Lord, 2004; Wolery & Garfinkle, 2002).

The literature review highlighted the dearth of practical, specific and validated outcome measures within the adult social skills literature. Social skills intervention studies with adults have mostly used social skills measures validated for a non-adult population (e.g. the Social Skills Rating System (SSRS; Gresham & Elliott, 1990). Social skills intervention studies may benefit from using the same primary outcome measure which would help to make comparisons between studies and consolidate the research base.

3.2. *Self-report and multiple informant measures.* Some researchers have raised concerns about the use of self-report measures among an ASD population given their reported difficulties with introspection and understanding their own mental states and emotions (Colle et al., 2007). For example, Berthoz and Hill's (2005) work on alexithymia found that those with ASDs were able to "*reliably reflect and report on their own emotions using self-report measures, but showed greater difficulties in identifying, verbalizing and analyzing their emotions*" (p.293). However, others have argued that self-report can be reliable and valid among this population (Sebastian et al., 2009). Indeed, the empirical paper highlighted that the participants were able to articulately reflect on their experiences of the intervention and exhibited both self-awareness and insight.

The use of multi informant measures (e.g. facilitator, parent, friend, etc.) may provide an additional layer of supporting evidence. An addition of a third party non biased informant such as a university tutor or employer may be particularly informative because they could provide behavioural ratings that are blind to the intervention. Further research however is needed to explore appropriate multi-informant measures and also investigate how these data sets relate to each other before they could be used reliably in intervention studies.

3.3. *Capturing the nuances and subtlety of behaviour change.* Qualitative research on psychosocial interventions for adults with ASDs is limited. Research has focused mainly on quantitative data, and has focused on the effectiveness of an intervention as opposed to the participants' experiences. Whilst this is useful, such research does not allow for subtle individual characteristics to be captured. The results of the empirical paper highlighted the value of qualitative exploring the experience of attending a social skills group. It provided information on the more subtle benefits of the intervention which would not have been captured on quantitative measures. How a participant experiences a social skills group is

under researched, particularly from a qualitative perspective. Qualitative sources of information are often overlooked, which is unfortunate as it is an important component of evaluating intervention effectiveness.

4. Making research accessible. It is important that participation in research is not limited by difficulties some individuals with ASDs may have. One interview was significantly shorter than the others; and the participant appeared to find the interview part of the assessment uncomfortable. On closer examination of transcript and clinical judgment during the interview, this may have been due to the individual having difficulties with the open-ended nature of the interview or finding social interaction situations difficult. Other methods of collecting data through written correspondence, via email, or interviews via Skype or telephone have been explored in other areas of research with considerable success (Holt, 2010; Hanna, 2012). Future qualitative research with an ASD population needs to offer these options to participants in order to help individuals who find direct social interaction difficult participate in research.

5. Intervention specific. The literature review highlighted the numerous variations of social skills interventions, and although the majority of the studies reported mostly positive results, the variation between interventions makes it difficult to conclude what makes an effective intervention. There seems to be a consensus that social skills interventions are beneficial, however the effective components of a successful intervention are still unknown.

5.1. Following guidelines. To address methodological challenges in research on psychosocial interventions for ASDs, Smith et al. (2007) developed a model or ‘road map’ for systematically validating and disseminating interventions in a sequence of steps. First, *“initial efficacy studies are conducted to establish interventions as promising. Next, promising interventions are assembled into a manual, which undergoes pilot-testing. Then,*

randomized clinical trials test efficacy under controlled conditions. Finally, effectiveness studies evaluate outcomes in community settings.” (Smith et al., 2007, p. 354).

The literature review highlighted a mixed picture in terms of where the evidence base is at in terms of the above guidelines. Some interventions seemed to have progressed to the third stage of RCT's (Laugeson et al., 2009; Gantman et al., 2012; Spek et al., 2013) whereas others reached the second stage of pilot-testing. Some studies did not assemble the intervention into a manual before piloting the intervention. Future research investigating the use of psychosocial interventions for adults with ASDs should follow the guidelines in order to consolidate the research base.

5.2. Treatment fidelity. Future studies should also undertake measures of treatment fidelity as failure of studies to provide intervention fidelity data makes it extremely difficult to conclude whether a social skills intervention was ineffective because of an ineffective intervention strategy or because the strategy was poorly implemented. Strategies such as videotaping observations for later scoring by independent raters can be used (Barlow & Hersen, 1984).

Future researchers need also to address the perceived conflict between the call for manual-based interventions and the need to be flexible in treatment planning to meet the individual needs of individuals with ASDs. A major challenge in developing an intervention manual is to balance uniformity with the need to individualize the intervention. MacMahon (2004) proposed “constrained flexibility” such that some variation in implementation is acceptable. For example, the manual may “*describe acceptable variations in delivering an intervention (e.g., alternate instructions and prompts) and courses of action if the initial implementation of the intervention is unsuccessful (e.g., possible modifications or other intervention techniques that can be introduced)*” (Smith et al., 2007, p. 359).

5.2. Investigating the “active ingredient”. There is also a need as part of developing and evaluating group interventions to explore the active ingredient (which components are most responsible for therapeutic effects) of successful interventions. This may include investigating the effects of dosage (duration and intensity of interventions), strategies used (e.g. modelling, role play) or the benefit of a support group format with no skill instruction.

The results of the empirical paper suggested that the process of meeting others with ASDs and having the opportunity to share personal experiences with individuals with similar difficulties was a significant benefit of the intervention. The universal experience of attending a group with similar people seemed to be an extremely powerful component of the group. It is therefore unclear whether the participants benefited from the Socialeyes intervention or whether a support group with others with ASDs would have resulted in similar benefits. Future research may consider comparing the effects of individuals with ASDs simply sharing experiences with a social skills group such as Socialeyes. Exploration of the active ingredients of successful interventions is needed.

Theoretical implications

1. Theory of group processes and its relevance to group social skills

interventions. Ormont (1992) reported that good general group process enables the members to see “*how others respond to them, affords people diverse views of their behaviour, provides the opportunity for on the spot reflection, and affords the chance to practice new behaviours.*” (p. 85)

The empirical paper findings appear to echo the group processes highlighted in the above quote. In addition to the above mentioned group processes, the participants and the facilitators spoke about a sense of acceptance within the group and the significant benefit of this.

The exact mechanism through which social skills groups change behaviour is not known, but is theoretically based on social learning theory (Bandura, 1977). Social skills groups for people with ASDs are thought to affect an individual's social functioning by providing instruction on specific social skills in a group format that allows for immediate rehearsal and practice of the learned skills (Reichow et al., 2013). The social skill group format also allows for “*immediate reinforcement for using the targeted skill (in an unstructured setting, the reinforcement for using a social skill might be social reinforcement, which may or may not be a reinforcer for an individual with ASD)*” (Reichow et al., 2013 p.6). Providing immediate reinforcement for displaying the desired (targeted) social skill should increase the likelihood of the skill being used again, thereby providing the individual with additional repetitions and practice (Reichow et al., 2013).

Gresham et al. (2001) identified a number of strategies to promote skill acquisition, generalization and maintenance, including teaching social skills in a natural setting, using active modelling of behaviours, and coaching and reinforcement procedures. Delivering social skills training in a group format may facilitate the use of these strategies by allowing individuals to practice social skills through interacting with their peers, with guidance from group facilitators. As the empirical paper highlighted, the participants stated that they wanted more opportunities to practice their skills and the group environment provides a perfect opportunity for this.

2. Advantages and limitations of group interventions for individuals with ASD.

Group interventions have several theoretical advantages over individual interventions which are outlined below.

2.1. Observation and modelling. Group-based instructions offer the advantage of allowing the participants to observe each other and facilitators as they practice and role play

the skills. This increases the likelihood of observational learning and allows the facilitators to point out the various ways in which the different participants executed the same skills correctly. The multiple exemplars help to demonstrate the degree of flexibility within social skills by illustrating the multiple ways of using a specific skill (e.g. numerous ways of starting a conversation).

2.2. Opportunities to practice skills. In comparison to individual interventions, group interventions provide immediate and natural opportunities for participants to practice newly learned social skills with peers (Barry et al., 2003). A group format provides a social platform for naturally occurring peer interaction, and provides the opportunity to practice newly learned skills in a relatively naturalistic format that may promote interaction outside of the group (Barry et al., 2003). Such a supportive learning atmosphere is especially important given that a majority of individuals with ASDs often have a history of negative, sometimes even hostile, peer interactions.

2.3 Meeting others with ASDs, sharing experiences, and developing friendships. Group based interventions may also result in group benefits including universality (recognizing common experiences among group members) and mutual support (Leszcz et al., 1985). Group interventions may provide opportunities for individuals to meet others with ASDs, which may be a novel experience for them. As was true for the participants in the empirical paper, having the opportunity to discuss daily challenges and struggles with others who saw and experienced things in a similar way seems to be very reassuring. Additionally simply being accepted by a group of individuals seemed to be a relatively unique experience for some in the group.

2.5. Cost and time effective. The cost-effectiveness of group treatment (i.e., fewer hours per individual) and its potential for seeing large numbers of individuals simultaneously

(reducing waiting lists) are further advantages, especially for those who may be working with limited resources.

2.6. Limitations of group interventions. Despite the many advantages of group interventions, for some individuals with ASDs a group intervention may not be the most appropriate and helpful approach. In a group intervention there are fewer opportunities to tailor the intervention to individual needs. In individual therapy the issues are discussed with one therapist, the highly personal nature of the exchange between the therapist and the client allows for specific focus on the issues presented. In a group intervention, issues are usually presented at group level and therefore have a less personal immediate feedback process.

For some individuals with ASDs a group intervention may be too overwhelming as a first line intervention (e.g. if an individual is feeling too anxious to attend). Therefore some individuals may need a preliminary individual intervention to prepare for the group intervention. Group social skills interventions often have relatively small numbers, however quieter individuals may get 'lost' in a group if other members are more talkative. The appropriateness and helpfulness of a group intervention should be assessed based on the individuals' needs.

Clinical implications

1. Effects of social skills deficits. Historically, the prognosis for individuals diagnosed with ASDs in childhood has been poor. Very few adults with ASDs live independently, get married, go to college, work in competitive jobs, or develop large social networks, and most individuals with ASDs remain dependent on their families or on professional service providers (Levy and Perry, 2011; Seltzer et al., 2004). Individuals with HFA/AS tend to have better quality of life outcomes in terms of independent living, education level and job placement (Cederlund et al., 2010; Howlin et al., 2004; Seltzer et al.,

2004). They however continue to have difficulty with social aspects of life and due to their high levels of intelligence, adults with AS/HFA are often painfully aware of their social skill difficulties (Levy and Perry, 2011).

Deficits in social functioning can significantly affect social interactions and interfere with the ability to establish lasting and meaningful friendships leading to rejection and isolation, which may in turn contribute to the emergence of mental health problems such as anxiety and depression (Tantam, 2000). La Greca and Lopez (1998) suggested that social skill deficits may lead to social anxiety by increasing the likelihood that the individual will experience negative peer interactions. Continued social isolation makes deficits in the knowledge of peer etiquette more obvious as the individual with ASD gets older. It often is assumed that individuals with ASDs prefer to be socially isolated from others. However, many people with ASDs are intensely aware of their isolation and are unhappy about their lack of social connectedness (Attwood, 2000).

Few previous studies have examined the broader outcomes for social skills interventions, such as a reduction in anxiety and depression, despite the prevalence of these comorbid conditions among those with ASDs. Certainly social skills, relationships with peers, and anxiety seem closely intertwined therefore addressing anxiety and depression within a social skills group intervention may improve other symptoms seen in ASDs (Kelly et al., 2008; Brereton et al., 2006). Given the pervasive and long-term nature of these deficits, social skills training interventions implemented early in life might prevent or at least attenuate subsequent social difficulties. There is therefore a clinical need to ensure that social skills difficulties are addressed early in life to help prevent negative outcomes for adults later in life.

2. Generalisation of skills. The ability to generalise learned social skills was a reported difficulty for some of the participants in the empirical study. Extensive evidence demonstrates that generalisation of skills often forms the most significant challenge for individuals with ASDs (Bellini, Peters, Benner, & Hopf, 2007). This was highlighted in the current study with some participants successfully generalising skills learnt to their everyday life and others finding this more difficult. The lack of reported generalisation of skills may be explained by many different factors. Previous research has stated that social skills must be learned in the context of social situations and in natural settings (Bellini, Peters, Benner, & Hopf, 2007). Although a group intervention provides opportunities for individuals to practice skills with one another, the classroom setting may not be generalisable to ‘real life’ situations for some participants.

Creating opportunities for individuals to practice their skills outside of the group (e.g. in a café, in a social club etc.) whilst being supported by facilitators and other participants may be an important consideration for future social skills interventions. The participants would therefore be able to practice their skills in real life situations but with added support and scaffolding in place.

3. “Going outside my comfort zone”. The theme of “*Going outside my comfort zone*” was identified in the empirical paper. Some of the participants reported that they felt a need to be challenged more within the group. The facilitators felt demands were carefully managed, and were tentative about placing more demands on the participants. The disparity between participants and facilitators accounts highlights the difficulty of assessing the appropriate pace and intensity of a group intervention. A safe, supportive, and validating environment seems fundamental in a group intervention, however the participants’ accounts suggest that support alone is not always sufficient for change.

The balance between support and challenge needs to be assessed regularly in order to encourage individuals to step out of their comfort zone in a safe manner. Interventions may therefore need to provide regular opportunities for participants to feedback. This could be in the form of an informal group discussion or in a written form if participants preferred.

Another suggestion would be to undertake a brief chat with every participant individually halfway through the intervention to assess each individual's progress and goals for the group. The sense of togetherness created within the group encouraged an ethos of belonging and safety and therefore seems to have provided the optimal environment in which social risks could be taken more easily.

Guidelines for interventions for individuals with ASD usually consist of lowering demands and paying careful consideration to the intensity and pace of the intervention in order to regulate anxiety levels. Although this is extremely important, in some cases there is a danger that doing this may reinforce a pattern of social avoidance and thus de-skill individuals.

Clinical and anecdotal accounts has highlighted that a common problem in high-functioning ASD is "*experiential avoidance that may arise from the vulnerability to stress and experiences of negative life events*" (Pahnke et al., 2013, p.2). Clinical interventions that encourage individuals to reduce avoidant behaviour may be beneficial for this population as a way of helping them step out of their comfort zone. Interventions such as Acceptance and Commitment therapy (Hayes, 2004) and Mindfulness (Kabat-Zinn, 1990) which are aimed at helping the individual cope with difficult thoughts, emotions and body sensations, thereby breaking experiential avoidance patterns may be helpful for this population.

4. Marketing and future plans of the Socialeyes intervention. One of the subordinate themes identified in the empirical paper was preconceptions about the group. The participants reported many expectations and worries about the group. These included

personal worries about their own social abilities, worries about the social abilities of the other members of the group and also misinterpretations about what would be expected of them in the group. There is therefore a need to address marketing of the Socialeyes group, in order to clear some misinterpretations and recruit more members. Future marketing would benefit from including reports from previous members of the group as member to member feedback is a much stronger form of marketing for interventions.

As a direct result of the success of the Socialeyes intervention, the University has agreed to provide a weekly, rolling program to its students with ASDs. This is of course a positive step however further research would be helpful to fully evaluate the effectiveness of the intervention. The University appears to have fully embraced the program and has agreed to award employability awards for participants who complete the program.

Personal reflections

Throughout my time as an Assistant Psychologist and a Trainee Clinical Psychologist I have had the opportunity to develop an interest in working with individuals with ASDs. More specifically how services are configured to support individuals, some of whom also have complex mental health difficulties. I have worked with individuals across the life trajectory from very young children with ASDs, to adolescents, adults and older adults. I feel that I have observed how ASDs can affect individuals at different life transitions. My previous experiences highlighted that with the right type of support individuals with ASDs could lead happy and contented lives and overcome the challenges that are inherent with their lifelong diagnosis.

Throughout this project I was encouraged to keep a record of my thoughts and reflections at each stage. After looking back at these a number of significant ones stood out. At the beginning of the project in order to further develop my understanding of ASDs I researched

around the area. I read research papers, book chapters and also ventured further afield to social media accounts of ASDs and came across countless blogs, Twitter accounts and YouTube videos from individuals with ASDs. I found this to be hugely informative and hearing the stories of people with first-hand experience gave me more motivation and a sense that this research could really be helpful.

This was my first experience of undertaking a full qualitative research project and I found the process both challenging and rewarding. I wanted to broaden my research experience and it was partly for this reason that I committed to using the methodology. The more I developed the narrative the more I was glad that I had persevered with the approach, as this client group is underrepresented in qualitative research. I had however underestimated the intensity of the process, and how time consuming each part of the analysis would be. The process of developing initial themes felt relatively easy with the data slotting quite neatly into the different themes. I felt curious as to why other trainees had reported that the process was stressful and difficult. I was however lured into a false sense of security as the following analysis process became extremely effortful and painstakingly slow. With guidance and support, the themes became clearer and the process appeared to make sense once again.

I felt the need to represent all of the participants and facilitators, and felt strongly that I wanted the paper to be a true reflection of each individual's story. I also felt myself becoming very protective of the data, and protective of my interpretation of the data which made it difficult to re-arrange or delete extracts. I was concerned about losing the individual narratives of the participants and facilitators, in order to pull together themes, and felt that everything I had heard was important, and that this should be reflected in some way. Having to delete some extracts from the paper felt very uncomfortable, however I learnt that this was a part of the analysis process and an essential component of qualitative analysis. I recall

hoping that the write-up would reflect a level of detail that participants would approve of, and I wondered what they would think about the quotes that I had chosen to illustrate themes.

Upon reflection my preconceptions of qualitative analysis were quite naive, with beliefs around adopting a purely objective stance of ‘giving voice’ to the participants’. Whilst preparing for the analysis, I gained an increasing appreciation of my active role within the analysis. Although I tried to remain relatively objective, I was very aware that my own values and experiences may influence the decisions that I made about the data. This reminded me of clinical practice, particularly the process of therapy, and how historically therapists were seen as blank canvases. In my experience this is far from reality, as individuals we have our own set of values, assumptions, within therapy efforts are made to manage these, through monitoring and clinical supervision. I was fortunate to have time to reflect on these issues and the influences that my assumptions, and experiences were having on the decisions made during the analysis process.

In the context of the wider project, I found interviewing participants both a privilege and a challenge. There were times when I was mindful of some frustration, especially when I was finding it difficult to keep a participant on track. I noticed this frustration when carrying out the analysis and working through the transcript of this particular participant for the first few times. I remember feeling annoyed when the participant glossed over a question that I felt was important and gave a long answer to something I expected would be brief. When I became aware of these feelings I stopped the analysis, took a break and returned after a few minutes, which allowed me to refocus.

Undertaking the interviews felt like a natural process however I had to continually remind myself that my role was as researcher, not therapist, and the people I was talking to were participants, not clients. I also found it quite difficult to suspend my clinical judgement and

critical thinking during the interviews. The nature of the interviews is a different type of enquiry to that which I am most comfortable with as a clinician, and I was aware of urges to gather the facts, create a chronology, and formulate and problem solve. Resisting urges to act as a therapist was very difficult especially when a participant spoke about barriers that he experienced when trying to implement skills. I think sometimes as a therapist it is easy to jump in and offer advice or support without fully understanding the client's perspective. Undertaking this research has reminded me how important it is to provide an un-interrupted space for individuals to tell their story, and to develop their own narrative in their own words.

References

- Attwood, T. (2000). Strategies for improving the social integration of children with Asperger's syndrome. *Autism*, 4(1), 85–100.
- Bandura, A. (1977). *Social learning theory*. Englewood Cliffs, NJ: Prentice-Hall.
- Barlow, D. H., & Hersen, M. (1984). *Single-case experimental designs: Strategies for studying behavior change* (2nd ed.) New York: Pergamon Press.
- Barry, T. D., Klinger, L. G., Lee, J. M., Palardy, N., Gilmore, T., & Bodin, S. D. (2003). Examining the effectiveness of an outpatient clinic-based social skills group for high-functioning children with autism. *Journal of Autism and Developmental Disorders*, 33, 685–701.
- Bauminger, N., Shulman, C., & Agam, G. (2003). Peer interaction and loneliness in high-functioning children with autism. *Journal of Autism and Developmental Disorders*, 33, 489–507.
- Bellini, S., Peters, J.K., Benner, L., & Hopf, A. (2007). A meta-analysis of schoolbased social skills interventions for children with autism spectrum disorders. *Remedial and Special Education*, 28(3), 153-162.
- Berthoz, S., & Hill, E. L. (2005). The validity of using self-reports to assess emotion regulation abilities in adults with autism spectrum disorder. *European Psychiatry*, 20, 291–298.
- Brereton, A. V., Tonge, B. J., & Einfeld, S. L. (2006). Psychopathology in children and adolescents with autism compared to young people with intellectual disability. *Journal of Autism and Developmental Disorders*, 36, 863–870.
- Cederlund, M., Hagberg, B., & Gillberg, C. (2010). Asperger syndrome in adolescent and young adult males. Interview, self and parent assessment of social, emotional, and cognitive problems. *Research in Developmental Disabilities*, 31, 287–298.
- Colle, L., Baron-Cohen, S., & Hill, J. (2007). Do children with autism have a theory of mind? A nonverbal test of autism vs. specific language impairment. *Journal of Autism and Developmental Disabilities*, 37, 716–723.

- Gantman, A., Kapp, S. K., Orenski, K., & Laugeson, E. A. (2012). Social skills training for young adults with high-functioning autism spectrum disorders: A randomized controlled pilot study. *Journal of Autism and Developmental Disorders*, 42(6), 1094-1103.
- Gresham, F. M., Sugai, G., & Horner, R. H. (2001). Interpreting outcomes of social skills training for students with high incidence disabilities. *Exceptional Children*, 67(3), 331-345.
- Gresham, F. M., & Elliott, S. (1990). *The social skills rating system*. Minnesota: American Guidance Service.
- Hanna, P. (2012). Using internet technologies (such as Skype) as a research medium: a research note. *Qualitative Research*, 12(2), pp. 239-242.
- Hayes, S. C. (2004). Acceptance and Commitment Therapy, relational frame theory, and the third wave of behavior therapy. *Behavior Therapy*, 35, 639-665.
- Holt, A. (2010). Using the telephone for narrative interviewing: a research note. *Qualitative Research* 10(1): 113-121.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 45, 212-229.
- Kabat-Zinn, J. (1990). *Full catastrophe living: How to cope with stress, pain and illness using mindfulness meditation*. New York: Dell.
- Kelly, A.B., Garnett, M.S., Attwood, T., & Peterson, C. (2008). Autism Spectrum Symptomatology in Children: The Impact of Family and Peer Relationships. *Journal of Abnormal Child Psychology*, 36, 1069-1081.
- La Greca, A. M., & Lopez, N. (1998). Social anxiety among adolescents: Linkages with peer relations and friendships. *Journal of Abnormal Child Psychology*, 26, 83-94.
- Laugeson, E. A., Frankel, F., Mogil, C., & Dillon, A. R. (2009). Parent-assisted social skills training to improve friendships in teens with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39, 596-606.

- Leszcz, M., Yalom, I.D., & Norden, M. (1985). The value of inpatient group psychotherapy: patients' perceptions. *International Journal of Group Psychotherapy*, 35, 411–433.
- Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders*, 5(4), 1271-1282.
- Lord, C., Rutter, M., DiLavore, P. D., & Risi, S. (2001). *Autism diagnostic observation schedule*. Los Angeles: Western Psychological Services.
- MacMahon, R. J. (2004). *The Fast Track Project*. Invited address given at the meeting of the NIH Working Group on Methodological Challenges in Autism Treatment Research, Sacramento, CA.
- Ormont, L. R. (1992). *The group therapy experience: From theory to practice*. New York: St. Martin's Press.
- Pahnke, J., Lundgren, T., Hursti, T., & Hirvikoski, T. (2013). Outcomes of an acceptance and commitment therapy-based skills training group for students with high-functioning autism spectrum disorder: A quasi-experimental pilot study. *Autism*, 1362361313501091.
- Reichow, B., Steiner, A. M., & Volkmar, F. (2013). Cochrane Review: Social skills groups for people aged 6 to 21 with autism spectrum disorders (ASD). *Evidence-Based Child Health: A Cochrane Review Journal*, 8(2), 266-315.
- Rutter, M., Le Couteur, A., & Lord, C. (2003). *Autism diagnostic interview-revised*. Los Angeles, CA: Western Psychological Services.
- Scahill, L., & Lord, C. (2004). Subject selection and characterization in clinical trials in children with autism. *CNS Spectrums*, 9, 22–32.
- Sebastian, C., Blakemore, S., & Charman, T. (2009). Reactions to ostracism in adolescents with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 39(8), 1122–1130.
- Seltzer, M., Shattuck, P., Abbeduto, L., & Greenberg, J. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews*, 10(4), 234–247.

- Smith, T., Scahill, L., Dawson, G., Guthrie, D., Lord, C., Odom, S., Rogers, S., & Wagner, A. (2007). Designing research studies on psychosocial interventions in autism. *Journal of Autism and Developmental Disorders*, 37, 354–366.
- Spek, A. A., van Ham, N. C., & Nyklíček, I. (2013). Mindfulness-based therapy in adults with an autism spectrum disorder: A randomized controlled trial. *Research in Developmental Disabilities*, 34(1), 246-253.
- Tantam, D. (2000). Psychological disorder in adolescents and adults with Asperger syndrome. *Autism*, 4(1), 47-62.
- Warren, Z., McPheeters, M. L., Sathe, N., Foss-Feig, J. H., Glasser, A., & Veenstra-VanderWeele, J. (2011). A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics*, 127, e1303-e1311.
- Wolery, M., & Garfinkle, A. N. (2002). Measures in intervention research with young children who have autism. *Journal of Autism and Developmental Disorders*, 32, 463–478.

Section 5: Ethics Appendix

Confirmation of Bangor University Liability Insurance

Haslwood House
60 Bishopsgate
London EC2N 4AW
Tel: 020 7847 8670
Fax: 020 7847 8689



TO WHOM IT MAY CONCERN

11 July 2013

Dear Sir/Madam

**BANGOR UNIVERSITY
AND ALL ITS SUBSIDIARY COMPANIES**

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following covers are currently in place:-

1. EMPLOYERS' LIABILITY

Certificate No.	Y016458QBEO113A/026
Period of Cover	1 August 2013 to 31 July 2014
Limit of Indemnity	£25,000,000 any one event unlimited in the aggregate.
Includes	Indemnity to Principals
Cover provided by	QBE Insurance (Europe) Limited and Excess Insurers.

2. PUBLIC AND PRODUCTS LIABILITY

Certificate of Entry No.	UM026/95
Period of Cover	1 August 2013 to 31 July 2014
Includes	Indemnity to Principals
Limit Of Indemnity	£50,000,000 any one event and in the aggregate in respect of Products Liability and unlimited in the aggregate in respect of Public Liability.
Cover provided by	U.M. Association Limited and Excess Cover Providers led by QBE Insurance (Europe) Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Susan Wilkinson
For U.M. Association Limited



U.M. Association Limited
Registered Office: Haslwood House, 60 Bishopsgate, London, EC2N 4AW
Registered in England and Wales No. 2731799

Confirmation of School of Psychology Ethical Approval

Dear Michael,

2013-12205 Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study

Your research proposal number 2013-12205 has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date. Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil McQuarrie

NHS Ethics Proposal: IRAS form

NHS REC Form

Reference:
14/WA0064

IRAS Version 3.5

Welcome to the Integrated Research Application System

IRAS Project Filter

The Integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
A feasibility study of Socialeyes for adults with ASDs

1. Is your project research?

Yes No

2. Select one category from the list below:

- Clinical trial of an Investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an Investigational medicinal product and an Investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

2a. Will the study involve the use of any medical device without a CE Mark, or a CE marked device which has been modified or will be used outside its intended purposes?

Yes No

2b. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? Yes No
- b) Will you be taking new human tissue samples (or other human biological samples)? Yes No
- c) Will you be using existing human tissue samples (or other human biological samples)? Yes No

3. In which countries of the UK will the research sites be located?(Tick all that apply)

England

Date: 07/02/2014

1

147525/562462/1/761

NHS REC Form

Reference:
14/WA0054

IRAS Version 3.5

<input type="checkbox"/> Scotland <input checked="" type="checkbox"/> Wales <input type="checkbox"/> Northern Ireland <p>3a. In which country of the UK will the lead NHS R&D office be located:</p> <input type="radio"/> England <input type="radio"/> Scotland <input checked="" type="radio"/> Wales <input type="radio"/> Northern Ireland <input type="radio"/> This study does not involve the NHS
<p>4. Which review bodies are you applying to?</p> <input checked="" type="checkbox"/> NHS/HSC Research and Development offices <input type="checkbox"/> Social Care Research Ethics Committee <input checked="" type="checkbox"/> Research Ethics Committee <input type="checkbox"/> National Information Governance Board for Health and Social Care (NIGB) <input type="checkbox"/> National Offender Management Service (NOMS) (Prisons & Probation) <p><i>For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.</i></p>
<p>5. Will any research sites in this study be NHS organisations?</p> <input type="radio"/> Yes <input checked="" type="radio"/> No
<p>6. Do you plan to include any participants who are children?</p> <input checked="" type="radio"/> Yes <input type="radio"/> No
<p>7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?</p> <input type="radio"/> Yes <input checked="" type="radio"/> No <p><i>Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.</i></p>
<p>8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?</p> <input type="radio"/> Yes <input checked="" type="radio"/> No
<p>9. Is the study or any part of it being undertaken as an educational project?</p> <input checked="" type="radio"/> Yes <input type="radio"/> No <p>Please describe briefly the involvement of the student(s): The student will help to collect the data at time point one (pre-intervention) and will subsequently help to analyse this baseline data.</p>

Date: 07/02/2014

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NHS REC Form

Reference:
14/WA0054

IRAS Version 3.5

8a. Is the project being undertaken in part fulfillment of a PhD or other doctorate?
 Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?
 Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?
 Yes No

Date: 07/02/2014

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147525/562462/1/761

NHS REC Form

Reference:
14/WA0054

IRAS Version 3.5

Integrated Research Application System
Application Form for Other clinical trial or investigation



Application to NH&H&C Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
 A feasibility study of Socialeyes for adults with ASDs

Please complete these details after you have booked the REC application for review.

REC Name:
North Wales REC - West

REC Reference Number:
14/WA0054

Submission date:
07/02/2014

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills In Adults with Autistic Spectrum Disorders: A Feasibility Study

A2-1. Educational projects

Name and contact details of student(s):

Student 1	
Title	Forename/Initials Surname Ms Ela Cernyw
Address	NWCPP, School of Psychology Bangor University, Bangor Gwynedd
Post Code	LL57 2DG
E-mail	pspefc@bangor.ac.uk
Telephone	01248382205
Fax	01248383718

Date: 07/02/2014

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NHS REC Form

Reference:
14/WA0054

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Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
 Doctorate in Clinical Psychology

Name of educational establishment:
 North Wales Clinical Psychology Programme
 School of Psychology
 Bangor University
 Bangor
 Gwynedd
 LL57 2DG

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Mike	Jackson
Address	Research Director, NWCPP School of Psychology, Bangor University Bangor, Gwynedd		
Post Code	LL57 2DG		
E-mail	mike.jackson@bangor.ac.uk		
Telephone	01248382205		
Fax	01248383718		

Academic supervisor 2

	Title	Forename/Initials	Surname
	Dr	Jessica	Eade
Address	Psychology Services, Betsi Cadwaladr University Health Board Hergest Unit, Ysbyty Gwynedd Bangor, Gwynedd		
Post Code	LL57 2PW		
E-mail	jessicaeade@hotmail.co.uk		
Telephone	01248363460		
Fax			

Academic supervisor 3

	Title	Forename/Initials	Surname
	Dr	Bethan	Henderson
Address	Psychology Services, Betsi Cadwaladr University Health Board Hergest Unit, Ysbyty Gwynedd Bangor, Gwynedd		
Post Code	LL57 2PW		
E-mail	bethanhenderson@aol.com		
Telephone	01248363460		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
 Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor

Date: 07/02/2014

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NHS REC Form

Reference:
14/WA0054

IRAS Version 3.5

details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Ms Eia Cernyw	<input checked="" type="checkbox"/> Dr Mike Jackson <input checked="" type="checkbox"/> Dr Jessica Eade <input checked="" type="checkbox"/> Dr Bethan Henderson

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- Student
 Academic supervisor
 Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname
	Dr Jessica Eade
Post	Clinical Psychologist
Qualifications	BSc (Hons) Psychology PhD Psychology Doctorate in Clinical Psychology
Employer	Betsi Cadwaladr University Health Board
Work Address	Psychology Services, Hergest Unit Ysbyty Gwynedd Bangor, Gwynedd
Post Code	LL57 2PW
Work E-mail	Jessica.Eade@wales.nhs.uk
* Personal E-mail	jessicaeade@hotmail.co.uk
Work Telephone	01248384121
* Personal Telephone/Mobile	
Fax	

* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Mr Hefin Francis
Address	School Manager, School of Psychology Bangor University Bangor, Gwynedd
Post Code	LL57 2AS
E-mail	h.francis@bangor.ac.uk

Date: 07/02/2014

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NHS REC Form

Reference:
14/WA0054

IRAS Version 3.5

Telephone 01248388339
Fax**A6-1. Research reference numbers. Please give any relevant references for your study:**

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number: 2013-12205
Protocol Version: Version 3
Protocol Date: 17/12/2013

Funder's reference number:

Project website:

Registry reference number(s):

The Department of Health's Research Governance Framework for Health and Social Care and the research governance frameworks for Wales, Scotland and Northern Ireland set out the requirement for registration of trials. Furthermore: Article 19 of the World Medical Association Declaration of Helsinki adopted in 2008 states that "every clinical trial must be registered on a publicly accessible database before recruitment of the first subject"; and the International Committee of Medical Journal Editors (ICMJE) will consider a clinical trial for publication only if it has been registered in an appropriate registry. Please see guidance for more information.

International Standard Randomised Controlled Trial Number (ISRCTN):

ClinicalTrials.gov Identifier (NCT number):

Additional reference number(s):

Ref.Number	Description	Reference Number

A6-2. Is this application linked to a previous study or another current application?
 Yes No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A8-1. Summary of the study. Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.

Socialeyes is an innovative learning resource developed by the National Autistic Society (NAS) Cymru and University of Wales, Newport. Socialeyes enables learners to explore social communication and interaction, facilitating social response flexibility. It is a manualised programme package that can be delivered by non-clinical staff who have a working knowledge of ASD and may be based in higher, further education and community projects. Our experience in mental health services suggests that a group Socialeyes programme could be an acceptable and effective way to address core deficits associated with autistic spectrum disorders (ASDs), promote social confidence and potentially reduce isolation and psychological distress. However, to date, no research has formally examined the effectiveness of Socialeyes. This study will evaluate the feasibility of delivering a Socialeyes group in a community, further and higher education setting, with facilitators from within each setting. Data generated from the study will be used to inform the development of a grant proposal for a Pilot RCT imbedded in a larger, multicentre RCT trial of the Socialeyes intervention for adults with ASDs.

Date: 07/02/2014

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NHS REC Form

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14/WA0054

IRAS Version 3.5

A8-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Purpose and design

The aim of this study is to evaluate the feasibility of the Socialeyes intervention for adults with ASDs. No previous evaluations of Socialeyes have been conducted so a decision was made to carry out a feasibility study. The aims of the study are to examine what it is like to facilitate and participate in a Socialeyes group, and to explore if there is any change in participant's social interaction style, social anxiety, distress and wellbeing after taking part in a 10-week programme. Three research sites will be used: (a) a further education college, (b) a higher education college, and (c) a community ASD support group. Facilitators from each organisational setting will run the groups, with 6-8 individuals participating in each group.

A mixed quantitative and qualitative study design will be utilised. Assessments will be conducted with participants at three time points, at: time 1 (baseline), time 2 (post-programme) and time 3 (3 month follow-up). During the first two assessments, participants will complete a questionnaire and a semi-structured interview, the assessments will be video-recorded and the participants' social interaction style during the interview will be subsequently coded independently by two coders. At the third time point, participants are only required to complete and return the questionnaire which will posted to them. Participants will be asked to identify an informant at the beginning of the study (e.g. a parent, student mentor, friend) who would be willing to complete a postal questionnaire commenting on the participant's social interaction style. The informant is required to complete this questionnaire at the same three time points as the participant. The final method of data collection is a time 2 (post-programme) interview with the Socialeyes facilitators to explore what it is like to run a Socialeyes intervention. Whilst this is not a large study, it is hoped that by collecting both quantitative and qualitative data from three sources from three different settings, that we will generate sufficient data to inform the development of a grant proposal for a Pilot RCT of the Socialeyes intervention.

Recruitment

Between 18 and 24 participants will be recruited to the study. They will be recruited from three sources. Bangor University and Coleg Menai student support services will recruit participants to the higher education and further education groups respectively, and a community group will be recruited from the Anglesey and Gwynedd ASD Support Group. At least one member of staff from each organisation has received Socialeyes facilitator training delivered by a NAS Socialeyes accredited trainer (December 2013). They will assist in the recruitment process, and host as a minimum, a 10-week Socialeyes programme in their organisation. All facilitators have experience of working with individuals with an ASD.

Inclusion criteria

- Documented evidence of a diagnosis of high functioning autism (HFA) or Asperger Syndrome from a health professional or allied health professional.
- Expressed commitment and willingness to attend weekly sessions for the duration of the programme.
- The capacity to consent to being in the study. This would also indicate that participants have sufficient language skills to take part in session discussions and be able to comprehend the written materials of the intervention.
- Age 16+

Exclusion criteria

- Inability to give informed consent.
- Unwilling to attend a group-based programme.
- Marked sensory impairments

Consent

Information sheets and consent forms have been prepared, and written consent will be obtained prior to the study commencing. Individuals will be informed that participation in the study is entirely voluntary and that they are free to withdraw at any time without giving a reason. If participants withdraw from the research study but want to carry on taking part in the Socialeyes intervention this will be allowed. The information sheets and consent forms will be translated into Welsh but the assessments will be conducted in English due to the linguistic capability of the Research Coordinator (Bethan Henderson).

Risks, burdens and benefits

Participants may feel uncomfortable meeting the researcher for the first time and answering questions. They may also feel uncomfortable being filmed during the interview. To minimise feelings of discomfort, the assessments (baseline and post-programme) will take somewhere known to the participant and they will be given the option of bringing a

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friend or family member along to support them. They will be told that the video footage will only be viewed by the research team, and that they can withdraw from the study at any time without giving a reason.

During the Sociateyes Intervention, participants will be encouraged to take part in group discussions and this may be uncomfortable and anxiety provoking for participants. They will be reassured, however, that they do not have to talk if they do not want to and they will not be put under pressure to do so.

Each Sociateyes group will consist of about 6 people who may be known to the participants or be students in their university or college. They will be asked to consider that all participants in the group will have a diagnosed ASD and by their inclusion in the group, other participants will know that they too have a diagnosis of ASD. If participants do not want other people to know that they have an ASD, they may not want to take part in this group. They will however, be reassured that at the start of the group that ground rules will be discussed and the need to respect each other and not talk about each other outside of the group will be an important rule.

Participants cannot be guaranteed that they will find the Sociateyes intervention beneficial. It is hoped, however, that participants have a positive experience and are provided with an opportunity to develop their social skills and social confidence. In addition, they may get a sense of satisfaction that the information obtained from the study will help improve the delivery of Sociateyes groups locally and help other people with social interaction and communication difficulties.

An internal policy on fieldworker safety will be adopted, which includes ensuring that a member of administrative staff is aware of the location of the interviews, and that the interviewer contacts the staff member after each interview is completed. In addition, BCUHB lone worker guidelines will be adhered to and a BCUHB lone worker alert device will be used.

Confidentiality

Personal contact details. Participants who wish to take part in the study will be asked to provide their contact phone numbers and postal addresses for the purpose of arranging assessments, sending out the time 3 questionnaires and distributing summaries of the research findings. Participants will also be asked to identify an informant and provide their contact details, so the informant can be sent information about the study and questionnaires if they consent to take part in the study.

Direct quotes. All interviews will be transcribed and analysed. Where direct quotations from participants are included in reports to illustrate themes, pseudonyms will be used to maintain anonymity and any other identifying information removed. Consent will be sought from participants to use direct quotations in this manner.

Audio/visual devices. All interviews will be recorded on a digital recording device. Digital files will be transferred to a PIN-protected memory device. During transcription, pseudonyms will be introduced. Once transcription and analysis is complete, the recordings will be destroyed. Anonymised transcripts will be stored in password protected files.

Storage of personal data on NHS, university and laptop computers. Personal data supplied by participants will be stored in a password-protected file on the Research Coordinator's computer for access by the researcher, and on an NHS computer for access by the Chief Investigator as part of the system to ensure researcher safety.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply:

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation

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- Cross-sectional study
 Database analysis
 Epidemiology
 Feasibility/ pilot study
 Laboratory study
 Metanalysis
 Qualitative research
 Questionnaire, interview or observation study
 Randomised controlled trial
 Other (please specify)

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

The aim of this feasibility study is to conduct a preliminary evaluation of the acceptability and effectiveness of the Socialeyes intervention for adults with ASDs

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

Specific objectives are:

- (a) To explore participants' and facilitators' experiences of taking part in a Socialeyes Intervention, and
 (b) To examine the impact of the intervention on reported and observed social awareness, social interaction, social communication, social anxiety, general wellbeing and distress.

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

Autistic spectrum disorders (ASDs) are pervasive developmental disorders that share common symptoms which include autism and Asperger syndrome. Both the DSM-V (APA, 2013) and ICD 10 (WHO, 1992) diagnostic systems outline a core set of impairments that individuals with ASDs share, namely: difficulties in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours. The term "spectrum" is utilised because there is an underlying continuum of difficulties that individuals may have, for example some people on the spectrum may have very limited language skills whereas others may have proficient language abilities. Some will have different degrees of learning disability whilst others will be of average intelligence or higher. Other characteristics which vary between individuals include special interests or obsessions, fixed and rigid routines, difficulty coping with change and sensory sensitivity. Consequently, some individuals with an ASD are able to live relatively independent lives whereas others require a lifetime of specialist support. The concept of a spectrum also encompasses the idea that many "normal" people will have ASD type traits. Therefore, whilst the concept of an ASD depends on a core set of difficulties, these are manifested differently between individuals and are on a continuum with "normal" behaviour.

Estimates of the prevalence of ASDs have increased dramatically over the last thirty years. It is now thought to be present in 0.5 to 1% of the population, and is three to four times more common in men than women (Baird et al., 2006; Brugha et al., 2007). A number of factors are thought to account for the rise in prevalence, including the broadening of the definition of ASD from the original one of autism; increasing public awareness of the signs of ASD; and the availability of effective diagnostic services for children and young people. It has been suggested that there are many undiagnosed cases of adults with ASD, especially among older adults (James et al., 2005). One reason for this is that assessments for ASD have only recently become available, have focussed on children, and adults have not had the opportunity to be diagnosed as having an ASD. The National Autistic Society, however, estimate that there could be over 500,000 adults in the UK who meet the criteria for an ASD (National Autistic Society, 2011), and these numbers are likely to increase as children and young adults who have received a diagnosis of ASD reach adulthood.

ASD services for children and young people in the UK are relatively well established. Clinical guidelines have been published on the recognition, referral and diagnosis of children and young people on the autistic spectrum (National Institute of Clinical Effectiveness [NICE], 2011). In addition, guidelines have been published on the management and support of children and young people on the spectrum. The guidelines recommend that specific social-communication interventions for the core features of autism that include play-based strategies with parents, carers and teachers should be utilised wherever possible to increase joint attention, engagement and reciprocal communication (NICE, 2013).

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As with other developmental disorders the symptoms of ASDs vary with age. It has been suggested, for example, that while the more overt symptoms of autism are at their most obvious in early childhood and often improve thereafter, the symptoms of Asperger syndrome become more obvious with the social and functional demands of adolescence (Bemey, 2004). Although the impact of ASD in adulthood will depend on an individual's presentation, the following areas have been highlighted as difficult for adults. Social relationships may be one-sided or absent rather than reciprocal, which can lead to isolation (Volmar & Klin, 2000). Communication difficulties may manifest themselves as a failure to use social niceties, an inability to read non-verbal cues and a tendency to interpret information literally (Barnhill, 2007). Repetitive and focussed activities may lead to a life which is characterised by a rigid routine, which again leads to further isolation. As a result individuals with an ASD may have difficulties in all areas of their lives including further and higher education, employment, managing finances, housing, and may find it difficult to access the support they need to lead fulfilling and independent lives.

A clinical guideline for adults on the autistic spectrum was recently published (NICE 2012) which recommended that a specialist community-based multidisciplinary team for adults with autism should be established. In many parts of the UK, however, specialist autism teams have yet to be set up and adults with ASDs have to be incorporated into existing services. Individuals who have a learning disability (i.e. an IQ of below 70) are able to access learning disability services. However, adults with ASD without a learning disability can only access services if they also have a mental health problem. Consequently, they may fall through a gap between learning disability and mental health services and are unable to access any formal service. Furthermore, mental health services are not sufficiently equipped to deal with individuals with an ASD, and will only address the presenting mental health symptoms, not the core underlying ASD difficulties such as social communication.

Few psycho-social interventions for the core symptoms of autism exist for adults. Indeed, in the clinical guideline for adults it was decided that where primary data from an adult population were absent it was valid to extrapolate from an autism population with a mean age of 15 years or above (NICE, 2012). Utilising such an approach the clinical guideline group reviewed the evidence for social learning interventions to improve social interaction skills. They concluded that whilst the evidence was limited, such interventions address an important area of difficulty for adults with ASDs, and recommended that a group-based social learning programme should be utilised with adults with autism without a learning disability who have identified problems with social interaction. They also recommended that the programme should include the following techniques: modelling, peer feedback, discussion and decision-making, explicit rule and suggested strategies for dealing with socially difficult situations (NICE, 2012).

A review of group-based social skills interventions for adolescents with ASDs aged between 10 and 20 years of age also concluded that research into the efficacy of social skills groups is inconclusive and no intervention can be said to be uniformly effective (McMahon et al., 2013). The authors, however, highlighted a number of methodological issues in the research which has evaluated social skills group and concluded that future research should employ more accurate, sensitive and comprehensive measurement approaches.

Socialeyes is an innovative learning resource developed by the National Autistic Society (NAS) Cymru and University of Wales, Newport. Its aim is to help learners explore the social world and become more confident in social situations. It has not been designed as a social skills training programme per se in that it does not tell learners how to change "inappropriate" social behaviour. It has been designed to help learners explore social interaction so that they can make an informed choice about how they might respond in similar situations; it aims to help learners develop their social response repertoire. The programme has eight learning modules: (a) starting a conversation, (b) eye contact, (c) personal space, (d) taking turns in a conversation, (e) keeping on topic, (f) talking about interests, (g) sensitive topics and (h) ending a conversation. Socialeyes uses a five step process to learning: What? Why? How? When? Try! These steps are used to progress through each module. They focus the learner, aiming to inform and encourage exploration and application of the module topic. Amongst the methods used are video modelling, modelling (by facilitators), role-play and self reflection. To date, no research has formally examined the effectiveness of intervention. Socialeyes training is readily available from the NAS and the NAS inform us that it is used by clinicians across the UK. Although they do not have any data on how widely and in what context it is currently utilised. This feasibility study will, therefore, evaluate the acceptability and effectiveness of Socialeyes as an intervention for improving social interaction skills with adults with ASDs.

A13. Please summarise your design and methodology. It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.

Recruitment

Between 18 and 24 participants will be recruited to the study. They will be recruited from three sources: Bangor University and Coleg Menai student support services will recruit participants to the higher education and further education groups respectively; and a community group will be recruited from the Anglesey and Gwynedd ASD Support Group. At least one member of staff from each organisation has received Socialeyes facilitator training delivered by a NAS Socialeyes accredited trainer (December 2013). They will assist in the recruitment process, and host as a

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minimum, a 10-week Socialeyes programme in their organisation. All facilitators have experience of working with individuals with an ASD.

Design and procedures

Facilitators in each organisation will identify potential participants. Individuals who meet the inclusion criteria and are currently receiving support from their service will be invited to an appointment where the Socialeyes programme and feasibility study will be described. Potential participants will also be given a study pack comprising: a participant invitation letter, participant information sheet explaining the aims of the study, and a consent form, will be given to individuals to read and they will be given an opportunity to ask questions about the study. If individuals decide to take part in the study they will be required to complete the consent form and return it to the group facilitator. Participants will be given the option to take the pack home to give them time to reflect on the study. Once consent forms have been received, the contact details of the participant will be passed to Research Co-ordinator (Bethan Henderson) who will arrange a baseline assessment appointment. Participants will be advised that baseline assessment can take place within a familiar setting e.g. their home, university, college and that, if they choose to, they may attend with their student mentor, support worker, tutor or a friend.

After the baseline assessment has been conducted with the required number of participants (6 to 8) at each organisation, the Socialeyes group Intervention will run for a minimum of 10 weeks, each session will last approximately 2 hours each week. At the end of the intervention, each participant will have a post-study assessment appointment with the Research Co-ordinator, and will be required to complete another postal assessment 3 months later.

A combination of quantitative and qualitative assessment methods will be utilised in the study. Data will be collected from participants, group facilitators and informants who have been identified by participants. An informant should be someone that knows the participant quite well, who can comment on their social communication and interaction style (e.g. a parent, student mentor or support worker). Data from participants and informants will be collected at baseline (Time 1), post-programme (Time 2) and at a three-month follow-up (Time 3). Data from facilitators will be collected at Time 2 only.

Participant data collection

At all time points, participants will be asked to complete four self-report measures comprising a total of 116 items, which should take approximately 30 minutes to complete (see questionnaire booklet).

At time 1 and 2, participants will also be asked to participate in a semi-structured interview, which is anticipated to last around 30 minutes. At time 1 the focus of the interview will be on the participant's perception of their social interaction style and social confidence, experience of social interaction, and their expectations of attending the Socialeyes programme (see the pre-programme Interview Schedule). At time 2, the focus of the interview will be on the participant's experience of the programme, their perceptions of how their social interaction style has been impacted, their perceived social confidence and to identify social-activity related goals (see the post-programme Interview Schedule).

During the course of the interview at baseline and post-programme, the interviewer will also invite the participant to take a break from the formality of the interview and to engage in a conversation for approximately 15 minutes. This conversation will provide opportunity for behavioural observation of the participant's conversational interchange. The interviewer will provide some structure including leads and prompts on a topic (such as music, pets, or sports). This style of observation activity is included in the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1989), an instrument for assessing and diagnosis autism.

It is envisaged that the assessment (self-report measures, interview, and conversation) at baseline and post-programme will take a total of 60 minutes to complete. The interview and conversation part of the assessment will be video-recorded with the consent of participants.

At 3 month follow-up, participants will be asked to complete the battery of four self-report measures only, and in an open-ended section of the questionnaire to reflect on their social activity goals as described at post-programme assessment.

Informant data collection

The informant will be asked to complete one 30 item self-report measure (15-20 minutes to complete) asking them to report on the participant's social awareness, interaction and communication skills. The measure will be completed at all 3 timepoints.

Facilitator data collection

An in-depth semi-structured interview will be conducted with one programme facilitator from each organisation immediately post programme; this will take approximately 30-45 minutes to complete. The focus of the interview will be

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to explore their experience of the training, the utility of the programme material, issues faced in recruitment and delivery of the programme; also, their perception of the impact of the programme, if any, on their institutions student support services (see Facilitator Interview Schedule). The interviews will be audio-recorded with the consent of the facilitators.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
 Management of the research
 Undertaking the research
 Analysis of results
 Dissemination of findings
 None of the above

Give details of involvement, or if none please justify the absence of involvement.

Jessica Eade and Bethan Henderson ran a pre-pilot Societeyes group with four individuals in Spring 2013. From the outset the participants in the group were informed that the intervention had not been used before and their views on the programme and how the intervention could be evaluated in the future were vital. The participants generously shared their opinions and from this we developed the current feasibility study. We will also share the results of this feasibility study with our current participants and welcome their feedback on the study.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 6000 characters).

Documented evidence of a diagnosis of high functioning autism (HFA) or Asperger Syndrome from a health professional or allied health professional.

Expressed commitment and willingness to attend weekly sessions for the duration of the programme.

The capacity to consent to being in the study. This would also indicate that participants have sufficient language skills to take part in session discussions and be able to comprehend the written materials of the intervention.

Age 16+

A17-2. Please list the principal exclusion criteria (list the most important, max 6000 characters).

Inability to give informed consent.

Unwilling to attend a group-based programme.

Marked sensory impairments (e.g. profound hearing or sight difficulties)

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:

- Total number of interventions/procedures to be received by each participant as part of the research protocol.
- If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?

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3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Complete time 1 (baseline) assessment	1	No	60	Dr. Bethan Henderson & Ela Cernyw in a location of the participants choosing
Complete time 2 (post-programme assessment)	1	No	60	Dr. Bethan Henderson in a location of the participants choosing
Complete time 3 (3 month follow-up) questionnaire	1	No	30	In participants' own homes
Informant time 1 (baseline) questionnaire	1	No	20	In informants' own homes
Informant time 2 (post-programme) questionnaire	1	No	20	In informants' own homes
Informant time 3 (3 month follow-up) questionnaire	1	No	20	In informants' own homes
Facilitator time 2 (post-programme) Interview	1	No	45	Dr. Bethan Henderson in a location of the Facilitator's choosing

A19. Give details of any clinical intervention(s) or procedure(s) to be received by participants as part of the research protocol. These include uses of medicinal products or devices, other medical treatments or assessments, mental health interventions, imaging investigations and taking samples of human biological material. Include procedures which might be received as routine clinical care outside of the research.

Please complete the columns for each intervention/procedure as follows:

- Total number of interventions/procedures to be received by each participant as part of the research protocol.
- If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
- Average time taken per intervention/procedure (minutes, hours or days).
- Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
10-week Socialeyes programme	10	-	2 hours	This will take place in either Coleg Menai, Bangor University student services or the Gwynedd & Anglesey Asperger/Autism Support Group. Each group will be facilitated by an individual from each organisation who has received Socialeyes facilitator training.

A20. Will you withhold an intervention or procedure, which would normally be considered a part of routine care?

Yes No

A21. How long do you expect each participant to be in the study in total?

Each participant will take part in a baseline assessment, complete the 10-week Socialeyes intervention and then complete a questionnaire 3 months after the intervention has finished, so approximately 6 months in total

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps

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would be taken to minimise risks and burdens as far as possible.

Participants may feel uncomfortable meeting the researcher for the first time and answering questions. They may also feel uncomfortable being filmed during the interview. To minimise feelings of discomfort, the assessments (baseline and post-programme) will take place somewhere known to the participant and they will be given the option of bringing a friend or family member along to support them. They will be told that the video footage will only be viewed by the research team, and that they can withdraw from the study at any time without giving a reason. If a participant does withdraw from the research study but wants to carry on taking part in the Socialeyes intervention, this will be allowed.

During the actual Socialeyes interventions, participants will be encouraged to take part in group discussions and this uncomfortable and anxiety provoking for participants. They will be reassured that they do not have to talk if they do not want to and they will not be put under pressure to do so.

Each Socialeyes group will consist of about 6 people who may be known to the participants or be students in their university or college. They will be asked to consider that all participants in the group will have a diagnosed Autism Spectrum Condition (ASC) and by their inclusion in the group, other participants will know that they too have a diagnosis of ASC. If participants do not want other people to know that they have an ASC, they may not want to take part in this group. They will however, be reassured that at the start of the group that ground rules will be discussed and the need to respect each other and not talk about each other outside of the group will be an important rule.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes No

A24. What is the potential for benefit to research participants?

Participants cannot be guaranteed that they will find the Socialeyes intervention beneficial. It is hoped, however, that participants have a positive experience and are provided with an opportunity to develop their social skills and social confidence. In addition, they may get a sense of satisfaction that the information obtained from the study will help improve the delivery of Socialeyes groups locally and help other people with social interaction and communication difficulties.

A25. What arrangements are being made for continued provision of the intervention for participants, if appropriate, once the research has finished? (May apply to any clinical intervention, including a drug, medical device, mental health intervention, complementary therapy, physiotherapy, dietary manipulation, lifestyle change, etc.)

It is hoped that once Socialeyes groups are set up and established in each organisation, and if participants and facilitators respond positively to the intervention, that the groups will continue to run after the feasibility study has been completed.

A26. What are the potential risks for the researchers themselves? (If any)

We do not anticipate there being any potential risks for the researchers, however, an internal policy on fieldworker safety will be adopted, which includes ensuring that a member of administrative staff is aware of the location of the interviews, and that the interviewer contacts the staff member after each interview is completed. In addition, BCUHB lone worker guidelines will be adhered to and a BCUHB lone worker alert device will be used.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

Facilitators in each organisation will identify potential participants. Individuals who meet the inclusion criteria and are

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currently receiving support from their service will be invited to an appointment where the Socaleyes programme and feasibility study will be described. Potential participants will also be given a study pack comprising: a participant invitation letter, participant information sheet explaining the aims of the study, and a consent form, to read and they will be given an opportunity to ask questions about the study. If individuals decide to take part in the study they will be required to complete the consent form and return it to the group facilitator. Participants will be given the option to take the pack home to give them time to reflect on the study.

Once consent forms have been received, the contact details of the participant will be passed to Research Co-ordinator (Bethan Henderson) who will arrange a baseline assessment appointment. Participants will be advised that baseline assessment can take place within a familiar setting e.g. their home, university, college and that, if they choose to, they may attend with their student mentor, support worker, tutor or a friend. In the study pack, potential participants are asked to identify an informant and when the Research Co-ordinator contacts the participant to arrange the baseline assessment, the contact details of the Informant will be passed onto her for her to contact the informant.

After the baseline assessment has been conducted with the required number of participants (6 to 8) at each organisation, the Socaleyes group intervention will run for a minimum of 10 weeks, each session will last approximately 2 hours each week.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes No

Please give details below:

Facilitators at each organisation will need to check through student records to ensure that each potential participant meets the inclusion criteria for the study, n.b. that they have a diagnosis of ASD.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

Yes No

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

A29. How and by whom will potential participants first be approached?

Potential participants will be approached by facilitators at each organisation. They will be approached on an individual basis, the intervention will be explained verbally and then a study information pack will be given to each individual to read at their leisure. The study information pack comprises a participant invitation letter, participant information sheet explaining the aims of the study and a consent form to potential participants.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

If individuals are interested in taking part in the study, they will be required to complete a consent form and return it to the Socaleyes facilitator in their organisation. All participants will be required to sign a consent form or they will not be allowed to take part in the study. To assist participants' choice of participation, information about the purpose of the study, the possible benefits and drawbacks will be provided. The Research Coordinator's contact information will be provided to all participants for any questions or concerns that they might have.

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<p>If you are not obtaining consent, please explain why not.</p>
<p>Please enclose a copy of the information sheet(s) and consent form(s).</p>
<p>A30-2. Will you record informed consent (or advice from consultees) in writing?</p> <p><input checked="" type="radio"/> Yes <input type="radio"/> No</p>
<p>A31. How long will you allow potential participants to decide whether or not to take part?</p> <p>They can take as much time as needed to decide from the time that they are approached until the required number of participants to run a Societeyes group have been recruited. However, once the group has started to run they will not be eligible to take part in the study.</p>
<p>A32. Will you recruit any participants who are involved in current research or have recently been involved in any research prior to recruitment?</p> <p><input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Not Known</p> <p><i>If Yes, please give details and justify their inclusion. If Not Known, what steps will you take to find out?</i></p> <p>We will ask group facilitators to enquire whether any potential participants are currently taking part in any social skills group external to their organisation (e.g. CAMHS or Specialist Children's Services), and if so they will not be eligible to take part in the current study.</p>
<p>A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)</p> <p>Participants must be able to converse in English to take part in the pre and post programme assessments, and also to participate in the Societeyes intervention as all the group documentation (e.g. handouts, worksheets and video clips) are in English. Consequently, only such individuals will be approached to take part in the study. Consent forms and participant information sheets will be available in large print for those who require it.</p>
<p>A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?</p> <p>The information sheets and consent forms will be translated into Welsh, and will be presented bilingually to potential research participants. The questionnaires will be in English, however, as the standardised measures are not available in the Welsh language. The assessments will also be conducted through the medium of the English language due to the linguistic abilities of the Research Co-ordinator, Bethan Henderson.</p>
<p>A34. What arrangements will you make to ensure participants receive any information that becomes available during the course of the research that may be relevant to their continued participation?</p> <p>The facilitators in each organisation will be contacted if any relevant information to their continued participation emerges and they will be asked to pass on this information to the participants in their Societeyes groups.</p>
<p>A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.</p> <p><input checked="" type="radio"/> The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.</p> <p><input type="radio"/> The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.</p>

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- The participant would continue to be included in the study.
 Not applicable – Informed consent will not be sought from any participants in this research.
 Not applicable – It is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A38. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

- Access to medical records by those outside the direct healthcare team
 Electronic transfer by magnetic or optical media, email or computer networks
 Sharing of personal data with other organisations
 Export of personal data outside the EEA
 Use of personal addresses, postcodes, faxes, emails or telephone numbers
 Publication of direct quotations from respondents
 Publication of data that might allow identification of individuals
 Use of audio/visual recording devices
 Storage of personal data on any of the following:
- Manual files including X-rays
 - NHS computers
 - Home or other personal computers
 - University computers
 - Private company computers
 - Laptop computers

Further details:

Personal contact details. Participants who wish to take part in the study will be asked to provide their contact phone numbers and postal addresses for the purpose of arranging assessments, sending out the time 3 questionnaires and distributing summaries of the research findings. Participants will also be asked to identify an informant and provide their contact details, so the informant can be sent information about the study and questionnaires if they consent to take part in the study.

Direct quotes. All interviews will be transcribed and analysed. Where direct quotations from participants are included in reports to illustrate themes, pseudonyms will be used to maintain anonymity and any other identifying information removed. Consent will be sought from participants to use direct quotations in this manner.

Audio/visual devices. All interviews will be recorded on a digital recording device. Digital files will be transferred to a PIN-protected memory device. During transcription, pseudonyms will be introduced. Once transcription and analysis is complete, the recordings will be destroyed. Anonymised transcripts will be stored in password protected files.

Storage of personal data on NHS, university and laptop computers. Personal data supplied by participants will be stored in a password-protected file on the Research Coordinator's computer for access by the researcher, and on an NHS computer for access by the Chief Investigator as part of the system to ensure researcher safety.

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A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

Participants will be assigned a pseudonym in order to preserve their anonymity. Identifiers will be excluded from the interview transcripts and the write-up of the findings.

Basic contact details re required for the purpose of sending out questionnaire packs, arranging interviews and forwarding the findings of the study. The information will be stored in password protected files, separately from the study data (i.e. questionnaire data and interview transcripts).

Video recordings of Interviews will be destroyed immediately following transcription and coding of the data.

Betsi Cadwaladr University Health Board policy on data protection and confidentiality will be followed.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

The Chief Investigator (Dr. Jessica Eade), the Research Coordinator (Dr. Bethan Henderson) and the doctoral student (Elsa Cemyw) will have access to personal data during the study.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
- 3 – 6 months
- 6 – 12 months
- 12 months – 3 years
- Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

- Yes No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

- Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

- Yes No

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A48-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

Yes No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A60. Will the research be registered on a public database?

The Department of Health's Research Governance Framework for Health and Social Care and the research governance frameworks for Wales, Scotland and Northern Ireland set out the requirement for registration of trials. Furthermore: Article 19 of the World Medical Association Declaration of Helsinki adopted in 2008 states that 'every clinical trial must be registered on a publicly accessible database before recruitment of the first subject'; and the International Committee of Medical Journal Editors (ICMJE) will consider a clinical trial for publication only if it has been registered in an appropriate registry. Please see guidance for more information.

Yes No

Please give details, or justify if not registering the research.

This is a feasibility study not a full clinical trial, therefore it will not be registered on a public database.

Please ensure that you have entered registry reference number(s) in question A6-1.

A61. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

Written feedback will be provided to research participants.

A63. Will you inform participants of the results?

Yes No

*Please give details of how you will inform participants or justify if not doing so.
A summary of the research findings will be sent to all participants.*

6. Scientific and Statistical Review

A64. How has the scientific quality of the research been assessed? Tick as appropriate:

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's Institution or host organisation
- Review within the research team

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- Review by educational supervisor
 Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
 The NHS Pathway to portfolio support for pilot / feasibility research grant proposal was reviewed by two anonymous reviewers as part of the process of obtaining funding. The proposal was subsequently amended in accordance with the reviewers' comments.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A68. How have the statistical aspects of the research been reviewed? Tick as appropriate:

- Review by independent statistician commissioned by funder or sponsor
 Other review by independent statistician
 Review by company statistician
 Review by a statistician within the Chief Investigator's Institution
 Review by a statistician within the research team or multi-centre group
 Review by educational supervisor
 Other review by individual with relevant statistical expertise
 No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

	Title	Forename/Initials	Surname
	Dr	Zoe	Hoare
Department	Chief Statistician		
Institution	NWORTH		
Work Address	The Normal Site		
	Bangor University, Bangor		
	Gwynedd		
Post Code	LL57 2PZ		
Telephone	01248388095		
Fax	01248382229		
Mobile			
E-mail	z.hoare@bangor.ac.uk		

Please enclose a copy of any available comments or reports from a statistician.

A67. What is the primary outcome measure for the study?

The Liebowitz Social Anxiety Scale (LSAS; Liebowitz, 1987) a 24-item measure designed to assess both fear and avoidance of social (e.g., going to a party, meeting strangers) and performance (e.g., taking a test, giving a report to a group) situations; the scale provides six scores representing total fear, total avoidance, fear of social situations, fear of performance situations, avoidance of social situations and avoidance of performance situations. It has been widely used with ASD samples.

A68. What are the secondary outcome measures? (if any)

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The General Health Questionnaire (GHQ; Goldberg, 1978) is available in a 28-item version. It assesses levels of current psychological distress, including somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. It has been widely used with ASD samples. The Warwick-Edinburgh Mental Well-being Scale (WEMWBS; Tennant et al., 2007), comprising of 14 positively worded items, will be used to measure aspects of positive mental health.

A89. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

Total UK sample size: 24
Total International sample size (Including UK):
Total in European Economic Area:

Further details:
Between 6 and 8 participants will be recruited at each research site.

A80. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.

The Socialeyes intervention has been designed as a small group intervention and the NAS recommends that approximately 6 to 8 people participate in the programme. In addition, because this is a small feasibility study, a pragmatic approach to recruitment was taken, and we decided to hold groups in three different settings, that is a community group and a further and higher education setting.

A81. Will participants be allocated to groups at random?

Yes No

A82. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The participants' self-report measures and the informants' measures will be analysed quantitatively. Descriptive statistics will be used at each time point, as the estimated sample size is not sufficiently large enough for the use of inferential statistics. Data from this feasibility study, however, will allow us to map out the participants' and informants' responses at each time point, and provide information on the utility of the outcome measures (e.g. missing data). This will provide a useful starting point for the development of a further pilot study and controlled trial of the intervention.

The pre- and post-programme interviews with participants, and the post-programme interviews with the group facilitators will be analysed qualitatively using a framework approach (Ritchie & Spencer, 1993). This involves summarising and classifying data within a thematic framework. The framework approach involves obtaining a detailed knowledge of the content of transcripts through in-depth reading and consideration; developing a thematic framework through identifying key issues within the data; applying the framework to the text of the data; arranging data according to each issue or theme identified, and finding associations and differences between them. The analytic framework will develop from ongoing discussions between researchers to ensure that the understandings which emerge are based on a joint perspective.

The video recording of the interview and conversation at time 1 and 2 will be observed and scored according to ADOG guidelines by two raters (the Research Co-ordinator and Chief Investigator). The ADOG guidelines focus on the qualitative elements of the participants' language, communication and reciprocal social interaction skills.

6. MANAGEMENT OF THE RESEARCH

A83. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

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	Title Forename/Initials Surname
	Dr Gemma Griffith
Post	Research Tutor
Qualifications	BSc (Hons) Psychology PhD Psychology
Employer	NWCPP, Bangor University
Work Address	School of Psychology Bangor University, Bangor Gwynedd
Post Code	LL57 2AS
Telephone	01248382205
Fax	01248383718
Mobile	
Work Email	g.m.griffith@bangor.ac.uk

AB4. Details of research sponsor(s)

AB4-1. Sponsor

Lead sponsor

Status: NHS or HSC care organisation **Commercial status:**
 Academic
 Pharmaceutical industry
 Medical device industry
 Local Authority
 Other social care provider (including voluntary sector or private organisation)
 Other

If Other, please specify:

Contact person

Name of organisation School of Psychology, Bangor University
Given name Hefin
Family name Francis
Address School of Psychology, Bangor University
Town/city Bangor
Post code LL57 2AS
Country UNITED KINGDOM
Telephone 01248388339
Fax 01248382599
E-mail h.francis@bangor.ac.uk

Is the sponsor based outside the UK?
 Yes No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

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A86. Has external funding for the research been secured?

Funding secured from one or more funders
 External funding application to one or more funders in progress
 No application for external funding will be made

What type of research project is this?

Standalone project
 Project that is part of a programme grant
 Project that is part of a Centre grant
 Project that is part of a fellowship/ personal award/ research training award
 Other

Other – please state:

Please give details of funding applications.

Organisation	NHS Pathway to portfolio support for pilot / feasibility research
Address	BCUHS, Wrexham Medical Institute Unit 5C, Wrexham Technology Park Wrexham
Post Code	LL13 7YP
Telephone	01978727502
Fax	
Mobile	
Email	JulieAJones@wales.nhs.uk

Funding Application Status: Secured In progress

Amount: £9920.40

Duration
 Years:
 Months: 12

if applicable, please specify the programme/ funding stream:
 What is the funding stream/ programme for this research project?
 Pathway to Portfolio Scheme

A87. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

Yes No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A88-1. How long do you expect the study to last in the UK?

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Planned start date: 01/11/2013
 Planned end date: 31/10/2014
 Total duration:
 Years: 0 Months: 11 Days: 31

A71-2. Where will the research take place? (Tick as appropriate)

- England
- Scotland
- Wales
- Northern Ireland
- Other countries in European Economic Area

Total UK sites in study 3

Does this trial involve countries outside the EU?
 Yes No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:

- NHS organisations in England
- NHS organisations in Wales
- NHS organisations in Scotland
- HSC organisations in Northern Ireland
- GP practices in England
- GP practices in Wales
- GP practices in Scotland
- GP practices in Northern Ireland
- Social care organisations
- Phase 1 trial units
- Prison establishments
- Probation areas
- Independent hospitals 1
- Educational establishments 2
- Independent research units
- Other (give details)

Total UK sites in study: 3

A75-1. What arrangements will be made to review interim safety and efficacy data from the trial? Will a formal data monitoring committee or equivalent body be convened?

This is a feasibility study of an intervention, not a clinical trial, as such a data monitoring committee has not been convened, but the data will be discussed at the Steering Group in due course.

If a formal DMC is to be convened, please forward details of the membership and standard operating procedures to the Research Ethics Committee when available. The REC should also be notified of DMC recommendations and receive summary reports of interim analyses.

A75-2. What are the criteria for electively stopping the trial or other research prematurely?

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As mentioned above, this is a feasibility study not a trial, so the intervention will run for a total of 10 weeks and will not be stopped prematurely.

A78. Insurance/ indemnity to meet potential legal liabilities

Note: In this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A78-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (NHS sponsors only)
 Other insurance or indemnity arrangements will apply (give details below)

Bangor University is a member of U.M. Association Ltd (UMAL)

Employers Liability cover is provided by QBE Insurance (Europe) Limited and Excess Insurers. Limit of indemnity: £25,000,000 any one event unlimited in the aggregate.

Public and Products Liability cover is provided by U.M. Association and Excess Cover Providers led by QBE Insurance (Europe) Limited. Limit of indemnity: £50,000,000 any one event and in the aggregate in respect of Products Liability and unlimited in the aggregate in respect of Public Liability.

Period of cover in all cases: 1 August 2013 to 31 July 2014.

Please enclose a copy of relevant documents.

A78-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
 Other insurance or indemnity arrangements will apply (give details below)

Bangor University is a member of U.M. Association Ltd (UMAL)

Employers Liability cover is provided by QBE Insurance (Europe) Limited and Excess Insurers. Limit of indemnity: £25,000,000 any one event unlimited in the aggregate.

Public and Products Liability cover is provided by U.M. Association and Excess Cover Providers led by QBE Insurance (Europe) Limited. Limit of indemnity: £50,000,000 any one event and in the aggregate in respect of Products Liability and unlimited in the aggregate in respect of Public Liability.

Period of cover in all cases: 1 August 2013 to 31 July 2014.

Please enclose a copy of relevant documents.

A78-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional

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Indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
 Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Bangor University is a member of U.M. Association Ltd (UMAL)

Employers Liability cover is provided by QBE Insurance (Europe) Limited and Excess Insurers. Limit of indemnity: £25,000,000 any one event unlimited in the aggregate.

Public and Products Liability cover is provided by U.M. Association and Excess Cover Providers led by QBE Insurance (Europe) Limited. Limit of indemnity: £50,000,000 any one event and in the aggregate in respect of Products Liability and unlimited in the aggregate in respect of Public Liability.

Period of cover in all cases: 1 August 2013 to 31 July 2014.

Please enclose a copy of relevant documents.

A77. Has the sponsor(s) made arrangements for payment of compensation in the event of harm to the research participants where no legal liability arises?

- Yes No

Please enclose a copy of relevant documents.

PART B: Section 7 - Children

1. Please specify the potential age range of children under 16 who will be included and give reasons for carrying out the research in this age group.

No participants under 16 will be included in the study. Potential participants in Coleg Menai (further education site) will be aged from 16 years upwards.

2. Indicate whether any children under 16 will be recruited as controls and give further details.

No participants under 16 will be included in the study.

3-2. Please describe the arrangements for seeking informed consent from a person with parental responsibility and/or from children able to give consent for themselves.

All participants will be given a study information pack and be required to give written consent before taking part in the study. For those participants aged between 16 and 18, information about the study will be sent to the person who has parental responsibility for the participant, and written consent from that person will also be required before the participant can take part in the study.

4. If you intend to provide children under 16 with information about the research and seek their consent or agreement, please outline how this process will vary according to their age and level of understanding.

No participants under the age of 16 will be included in the study.

Copies of written information sheet(s) for parents and children, consent/assent form(s) and any other explanatory material should be enclosed with the application.

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PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name	Bangor University	Title	Ms.
Department name	Student Services	First name/ Initials	Esther
Street address	Neuadd Rathbone	Surname	Griffiths
Town/city	Bangor, Gwynedd		
Post Code	LL57 2DF		
Institution name	Coleg Menai	Title	Ms.
Department name	Learning Support Services	First name/ Initials	Sharon
Street address	Ffriddoedd Road	Surname	O'Connor
Town/city	Bangor, Gwynedd		
Post Code	LL57 2TP		
Institution name	Gwynedd Council	Title	Mr.
Department name	Gwynedd & Ynys Môn Social Services	First name/ Initials	David
Street address	Arlon Area Office, Penrallt	Surname	Oliver
Town/city	Caernarfon, Gwynedd		
Post Code	LL55 1BN		

PART D: Declarations**D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
 - May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. I understand that the main REC or its operational managers may share information in this application or supporting documentation with the Medicines and Healthcare products Regulatory Agency (MHRA) where it is relevant to the Agency's statutory responsibilities.
12. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication/(Not applicable for R&D Forms)

NRES would like to include a contact point with the published summary of the study for those wishing to seek further

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Information. We would be grateful if you would indicate one of the contact points below.

- Chief Investigator
- Sponsor
- Study co-ordinator
- Student
- Other – please give details
- None

Access to application for training purposes (Not applicable for R&D Forms)
Optional – please tick as appropriate:

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Dr. Jessica Eade on 07/02/2014 12:32.

Job Title/Post: Clinical psychologist
 Organisation: BCUHB
 Email: Jessicaeade@hotmail.co.uk
 Signature:
 Print Name: Dr. Jessica Eade
 Date: 07/02/2014 (dd/mm/yyyy)

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D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A75, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

This section was signed electronically by Mr Heffm Francis on 07/02/2014 13:00.

Job Title/Post: Manger of the School of Psychology
Organisation: Bangor University
Email: h.francis@bangor.ac.uk

Date: 07/02/2014

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147525/562462/1/761

NHS REC Form

Reference:
14/WA0054

IRAS Version 3.5

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr. Bethan Henderson on 07/02/2014 11:52.

Job Title/Post: Clinical Psychologist
 Organisation: Betsi Cadwaladr University Health Board
 Email: bethanhenderson@aol.com

Academic supervisor 2

This section was signed electronically by Dr. Jessica Eade on 07/02/2014 12:25.

Job Title/Post: Clinical psychologist
 Organisation: BCUHB
 Email: Jessceade@hotmail.co.uk

Academic supervisor 3

This section was signed electronically by Dr Mike Jackson on 07/02/2014 12:37.

Job Title/Post: clinical psychologist
 Organisation: bcuhb
 Email: mike.jackson@wales.nhs.uk

Date: 07/02/2014

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147525/562462/1/761

North Wales Research Ethics Committee – West: Letter of favourable opinion with additional conditions

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a arllwng gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

NISCHR
Gwasanaeth Moseg Ymchwil | Research Ethics Service

RES

Pwyllgor Moseg Ymchwil Gogledd Cymru - Y Orilewin
North Wales Research Ethics Committee - West

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: rossela.roberts@wales.nhs.uk
Website: www.nres.nhs.uk

Dr Jessica Eade
Clinical Psychologist
Betsi Cadwaladr University Health Board
Psychology Services, Hergest Unit
Ysbyty Gwynedd
Bangor, Gwynedd
LL57 2PW
jessica.eade@wales.nhs.uk

24 February 2014

Dear Dr Eade

Study title: Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study

REC reference: 14/WA/0064
Protocol number: 2013-12205
IRAS project ID: 147525

The Research Ethics Committee reviewed the above application at the meeting held on 20 February 2014. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Dr Rosseia Roberts, rossela.roberts@wales.nhs.uk

Ethical opinion

Ethical issues raised by the Committee in private discussion, together with responses given by you and Dr Jackson when invited into the meeting

Recruitment arrangements: fair participant selection

The Committee was satisfied that the selection of potential participants has taken into account their clinical care and sufficient details are provided in the protocol and the application form regarding the inclusion and exclusion criteria.

The Committee requested a clarification of the answer provided to question A72 of the application form which lists among the sites 'Independent hospitals'. You confirmed that this was ticked in error.

The Committee raised no further issues in relation to the recruitment arrangements.



Cyhoir Cytweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Adysgwyr Iechyd Powys
The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



14/WA/0064

Page 2 of 6

Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality

The Committee discussed the Information governance aspects of the study; questions were raised in relation to where and for how long will data be stored, and who will have access to the data, as the application form states that data will be stored on a laptop.

You clarified that this is an NHS encrypted and password protected laptop designated specifically for this research.

No further ethical issues were raised in relation to data protection.

Informed Consent process; adequacy and completeness of Participant Information

The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions. The information is clear as to what the participant consents and there is no inducement or coercion.

A clarification was requested regarding the 'video-modelling'; you clarified that it is a DVD containing video recording of a person demonstrating the skill that participants are learning on that day.

The Committee queried whether parental consent is required for participants aged 16 to 18.

You clarified that the facilitator in Coleg Menai advised that parental consent would be required for insurance purposes. The Committee noted that in this case parental consent would be required for informants who may be aged 16 to 18. The investigators agreed to consider how best to address this issue.

The Committee queried whether it is useful to inform the GP/clinician about the person's participation in the study; you clarified that the team would not know who the GP/clinical care team would be as participants are contacted via student support services; the team do not anticipate any problems to occur as a consequence of the person's participation in the study, however, any signs of distress or difficulties would be identified by the group facilitators who would act on this information in their capacity as students' counselors.

The Committee agreed that the procedures described in the protocol have been adequately addressed in the Information Sheets, but a minor amendment is required to clarify that should an informant withdraw, or a participant no longer want a person to act as their informant, it will not affect their ability to participate in the study.

The Chairman thanked you and Dr Jackson for your availability to speak to this submission and gave you an opportunity to ask questions. You did not raise any issues.

The Committee considered your responses.

On the basis of the information provided, the Committee was satisfied with the following aspects of the research:

- Social or scientific value; purpose and need; scientific design and conduct of the study
- Independent review
- Recruitment arrangements; fair participant selection
- Favourable risk benefit ratio; anticipated benefits/risks for research participants
- Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality
- Informed Consent process;
- Suitability of the applicant and facilities
- Suitability of the study summary

The Committee identified issues with the following aspects of the research:

- Adequacy and completeness of Participant Information

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. The Committee requested that the Information Sheet clarifies that should an informant withdraw (or a participant no longer want a person to act as their informant) it will not affect their ability to participate in the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.

The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

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Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
REC application (submission 147525/562462/1/761)		07 February 2014
Protocol	3	17 December 2013
Summary/Synopsis		
Letter of invitation to participant	2	09 January 2014
Letter of invitation to participant: Parent	1	09 January 2014
Letter of invitation to participant: Informant	2	09 January 2014
Letter of invitation to participant: Facilitator	2	09 January 2014
Participant Information Sheet	4	09 January 2014
Participant Information Sheet: Informant	2	09 January 2014
Participant Information Sheet: Facilitator	2	09 January 2014
Participant Consent Form	1	09 January 2014
Participant Consent Form: Parent	1	09 January 2014
Participant Consent Form: Informant	1	07 January 2014
Participant Consent Form: Facilitator	1	07 January 2014
Interview Schedules/Topic Guides Participant baseline	1	09 January 2014
Interview Schedules/Topic Guides Participant post-programme	1	09 January 2014
Interview Schedules/Topic Guides Facilitator Post-programme	1	09 January 2014
Questionnaire: Self-report questionnaire		
Questionnaire: Informant measure		10 January 2014
Referees or other scientific critique report		
Other: Response to scientific critique report		10 December 2013
Letter from Funder		15 January 2014
Letter from Sponsor	e-mail	21 January 2014
Evidence of insurance or indemnity		11 July 2013
Investigator CV (Dr Jessica Eade)		09 January 2014
Other: Student CV (Ms Ella Cernyw)		07 February 2014
Other: Academic Supervisor CV (Dr Mike Jackson)		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Mr Alwyn Rowlands declared a conflict of interest in relation to this application; the Committee decided that this does not constitute a conflict of interest and Mr Rowlands may remain in the room and participate in the review.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

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After ethical reviewReporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

14/WA/0064	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely


 Mr Derek James Crawford, MBChB, FRCGS
 Chair
 E-mail: rossela.roberts@wales.nhs.uk

Enclosure: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy:

Sponsor: Mr Hefin Francis
 School Manager, School of Psychology, Bangor University
 Brigantia Building, Penrallt Rd
 Bangor, Gwynedd, LL57 2AS h.francis@bangor.ac.uk

Student: Ms Eia Cernyw
 NWCPP, School of Psychology
 Bangor University
 Bangor, Gwynedd, LL57 2DG pspefc@bangor.ac.uk

Academic Supervisor: Dr Mike Jackson
 Consultant Clinical Psychologist
 BCUHB, Ysbyty Gwynedd
 Hergest Unit,
 Bangor, Gwynedd
 LL57 2PW mike.jackson@wales.nhs.uk

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North Wales Research Ethics Committee West
Attendance at Committee meeting on 20 February 2014

Committee Members

Name	Profession	Capacity	Present
Dr. Karen Addy	Clinical Psychologist	Expert	Yes
Dr. Swapna Alexander	Consultant Physician	Expert	Yes
Mrs. Kathryn Chester	Research Nurse	Expert	Yes
Dr. Christine Clark	Consultant Obstetrician & Gynaecologist	Expert	Yes
Mr. Derek James Crawford	Retired Consultant Surgeon (Chairman)	Expert	No
Mrs. Gwen Dale-Jones	Retired Personal Assistant	Lay +	Yes
Mr. Eilezer Lichtenstein	Student	Lay +	Yes
Dr. Mark Lord	Consultant Pathologist	Expert	Yes
Dr. Paul Mullins	Senior Lecturer, MRI Physicist	Lay +	Yes
Mr. Vishwanath Puranik	Associate Specialist ENT Surgeon	Expert	Yes
Mrs. Lynn Roberts	Matron, Emergency Department	Expert	Yes
Mr. David Alwyn Rowlands	Retired Development & Monitoring Officer	Lay +	Yes
Dr. Jason Walker	Consultant Anaesthetist	Expert	Yes
Dr. Phillip Wayman White	General Practitioner (Vice-Chairman)	Expert	Yes
Ms. Sydna Ann Williams	Lecturer	Lay +	Yes

Deputy Members

Name	Profession	Capacity	Present
Dr. Michael Cronin	Consultant Paediatrician (deputy to Dr. Clark)	Expert	No

In attendance

Name	Position (or reason for attending)
Dr. Rossela Roberts	Clinical Governance Officer / Committee Coordinator

North Wales Research Ethics Committee – West: Acknowledgement of documents in compliance with additional conditions

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o safon iechyd ymchwil Cymru a arferir trï gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

NISCHR
Gwasanaeth Moeleg Ymchwil | **RES** | Research Ethics Service

Pwyllgor Moeleg Ymchwil Gogledd Cymru - Y Ddrilewin
North Wales Research Ethics Committee - West

Betsi Cadwaladr - University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rosula.Roberts@wales.nhs.uk
Website: www.nres.nhs.uk

Dr Jessica Eade
Clinical Psychologist
Betsi Cadwaladr University Health Board
Psychology Services, Hergest Unit
Ysbyty Gwynedd
Bangor, Gwynedd
LL57 2PW

jessica.eade@wales.nhs.uk

28 February 2014

Dear Dr Eade

Study title: Exploring the Effectiveness of the Socialaya Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study

REC reference: 14/WA/0064
Protocol number: 2013-12205
IRAS project ID: 147525

Thank you for your letter of 28 February 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 24 February 2014

Documents received

The documents received were as follows:

Document	Version	Date
Participant Information Sheet	5	09 January 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
REC application (submission 147525/562462/1/761)		07 February 2014
Protocol	3	17 December 2013
Summary/Synopsis		
Letter of invitation to participant	2	09 January 2014
Letter of invitation to participant: Parent	1	09 January 2014
Letter of invitation to participant: Informant	2	09 January 2014
Letter of invitation to participant: Facilitator	2	09 January 2014
Participant Information Sheet	5	09 January 2014
Participant Information Sheet: Informant	2	09 January 2014
Participant Information Sheet: Facilitator	2	09 January 2014

(continued overleaf)



GIG NHS
GIG NHS
GIG NHS

Cysbeir Cymdeithasol Gweyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Iwrdal Addysgu Iechyd Powys
The National Institute for Social Care and Health Research Academic Health Science
Collaboration is hosted by Powys Teaching Health Board



Arweini gan
Llywodraeth Cymru
Funded by
Welsh Government

14/WA/0064

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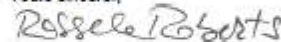
(continued from previous page)

Document	Version	Date
Participant Consent Form	1	09 January 2014
Participant Consent Form: Parent	1	09 January 2014
Participant Consent Form: Informant	1	07 January 2014
Participant Consent Form: Facilitator	1	07 January 2014
Interview Schedules/Topic Guides Participant baseline	1	09 January 2014
Interview Schedules/Topic Guides Participant post-programme	1	09 January 2014
Interview Schedules/Topic Guides Facilitator Post-programme	1	09 January 2014
Questionnaire: Self-report questionnaire		
Questionnaire: Informant measure		10 January 2014
Referees or other scientific critique report		
Other: Response to scientific critique report		10 December 2013
Letter from Funder		15 January 2014
Letter from Sponsor	e-mail	21 January 2014
Evidence of insurance or indemnity		11 July 2013
Investigator CV (Dr Jessica Eade)		09 January 2014
Other: Student CV (Ms Ela Cemyw)		07 February 2014
Other: Academic Supervisor CV (Dr Mike Jackson)		

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/WA/0064	Please quote this number on all correspondence
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Yours sincerely



Dr Rossela Roberts
Committee Co-ordinator
E-mail: rossela.roberts@wales.nhs.uk

Copy:

Sponsor: Mr Hefin Francis
School Manager, School of Psychology, Bangor University
Brigantia Building, Penrallt Rd
Bangor, Gwynedd, LL57 2AS h.francis@bangor.ac.uk

Student: Ms Ela Cemyw
NWCPP, School of Psychology
Bangor University
Bangor, Gwynedd, LL57 2DG pspefo@bangor.ac.uk

Academic Supervisor: Dr Mike Jackson
Consultant Clinical Psychologist
BCUHB, Ysbyty Gwynedd
Hergest Unit,
Bangor, Gwynedd
LL57 2PW mike.jackson@wales.nhs.uk

Confirmation of Research and Development Approval



Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D R&D Internal Review Panel

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Dr Jessica Eade
Psychology Services
Hergest Unit
Ysbyty Gwynedd
Bangor
LL57 2PW Jessicaeade@hotmail.co.uk

Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
Email: roszela_richards@wales.nhs.uk
wendy.scrape@wales.nhs.uk
sion.lewis@wales.nhs.uk
Tel/Fax: 01248 384 877

8 April 2014

Dear Dr Eade

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title Exploring the Effectiveness of the Socialeyes for adults with ASDs
IRAS reference 147525
REC reference 14/WA/0064

Thank you for submitting your R&D application and supporting documents.

The above study was eligible for Proportionate Review and was reviewed by the R&D Manager and Chairman of the Internal Review Panel.

The Committee is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Proportionate Review Committee is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below:

Documents Reviewed:	Version	Date
R&D Form – 147525/579508/14/453	-	13/03/2014
R&D Checklist	-	-
Protocol	3	17/12/2013
Invitation letter - participant	2	09/01/2014
Invitation letter – parent	1	09/01/2014
Invitation letter – informant	2	09/01/2014
Invitation letter - facilitator	2	09/01/2014
Participant Information Sheet	5	09/01/2014
Participant Information Sheet - facilitator	2	09/01/2014
Participant Information Sheet - informant	2	09/01/2014
Consent Form - participant	1	09/01/2014
Consent Form - parent	1	09/01/2014
Consent Form - informant	1	07/01/2014
Consent Form - Facilitator	1	07/01/2014
Interview schedule - facilitator	1	09/01/2014
Interview schedule - participant time 1	1	09/01/2014
Interview schedule - participant time 2	1	09/01/2014
Questionnaire – Self-report questionnaire	-	09/01/2014
Questionnaire – Informant measure	1	10/01/2014
SL5 Favourable opinion with additional conditions 14/WA/0064	-	24/02/2014
SL44 Acknowledgement of documents in compliance with additional conditions 14/WA/0064	-	28/02/2014

Confirmation of Pathway to Portfolio Funding Letter - Dr J Eade	-	15/01/2014
pathways to portfolio funding proposal reviews	-	-
PsP response to reviewer comments	-	10/12/2013
UMAL Insurance Bangor University 2013-2014	-	11/07/2014
CV - Cl - Dr Jessica Eade	-	09/01/2014
CV - Bethan Henderson	-	-
CV - Mike Jackson	-	-
CV - Ela Cemyw	1	12/08/2014

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database.

To apply for adoption onto the NISCHR CRP, please go to:
<http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>.

Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571> and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:

http://www.cmcc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.

Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office.

If you need any support in uploading this data, please contact wendy.scrase2@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours sincerely,



Dr Nefyn Williams PhD, FRCGP
 Associate Director of R&D
 Chairman Internal Review Panel

Copy to: Sponsor: Mr Hefin Francis
School Manager
School of Psychology
Bangor University
Bangor
LL57 2DG h.francis@bangor.ac.uk

PhD Student: Ms Eia Cemyw
North Wales Clinical Psychology Programme
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Bangor
LL57 2DG pspefc@bangor.ac.uk
Phone 01248382205

Academic Supervisor: Dr Mike Jackson
Research Director
North Wales Clinical Psychology Programme
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LL57 2DG mike.jackson@bangor.ac.uk

Academic Supervisor: Dr Bethan Henderson
Psychology Services
Hergest Unit
Ysbyty Gwynedd
Bangor
LL57 2PW bethanhenderson@api.com

Amendment to IRAS form

Notice of Amendment

IRAS Version 3.5

Welcome to the Integrated Research Application System
IRAS Project Filter
<p>The Integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.</p>
<p>Please enter a short title for this project (maximum 70 characters) A feasibility study of Socialeyes for adults with ASDs</p>
<p>1. Is your project research?</p> <p><input checked="" type="radio"/> Yes <input type="radio"/> No</p>
<p>2. Select one category from the list below:</p> <p><input type="radio"/> Clinical trial of an Investigational medicinal product</p> <p><input type="radio"/> Clinical investigation or other study of a medical device</p> <p><input type="radio"/> Combined trial of an Investigational medicinal product and an Investigational medical device</p> <p><input checked="" type="radio"/> Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice</p> <p><input type="radio"/> Basic science study involving procedures with human participants</p> <p><input type="radio"/> Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology</p> <p><input type="radio"/> Study involving qualitative methods only</p> <p><input type="radio"/> Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)</p> <p><input type="radio"/> Study limited to working with data (specific project only)</p> <p><input type="radio"/> Research tissue bank</p> <p><input type="radio"/> Research database</p> <p>If your work does not fit any of these categories, select the option below:</p> <p><input type="radio"/> Other study</p>
<p>2a. Will the study involve the use of any medical device without a CE Mark, or a CE marked device which has been modified or will be used outside its intended purposes?</p> <p><input type="radio"/> Yes <input checked="" type="radio"/> No</p>
<p>2b. Please answer the following question(s):</p> <p>a) Does the study involve the use of any ionising radiation? <input type="radio"/> Yes <input checked="" type="radio"/> No</p> <p>b) Will you be taking new human tissue samples (or other human biological samples)? <input type="radio"/> Yes <input checked="" type="radio"/> No</p> <p>c) Will you be using existing human tissue samples (or other human biological samples)? <input type="radio"/> Yes <input checked="" type="radio"/> No</p>
<p>3. In which countries of the UK will the research sites be located?(Tick all that apply)</p> <p><input type="checkbox"/> England</p>

1

147525/675609/13/611/33774

Notice of Amendment

IRAS Version 3.5

<input type="checkbox"/> Scotland <input checked="" type="checkbox"/> Wales <input type="checkbox"/> Northern Ireland
3a. In which country of the UK will the lead NHS R&D office be located: <input type="radio"/> England <input type="radio"/> Scotland <input checked="" type="radio"/> Wales <input type="radio"/> Northern Ireland <input type="radio"/> This study does not involve the NHS
4. Which review bodies are you applying to? <input checked="" type="checkbox"/> NHS/HSC Research and Development offices <input type="checkbox"/> Social Care Research Ethics Committee <input checked="" type="checkbox"/> Research Ethics Committee <input type="checkbox"/> National Information Governance Board for Health and Social Care (NIGB) <input type="checkbox"/> National Offender Management Service (NOMS) (Prisons & Probation) <i>For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.</i>
5. Will any research sites in this study be NHS organisations? <input type="radio"/> Yes <input checked="" type="radio"/> No
6. Do you plan to include any participants who are children? <input checked="" type="radio"/> Yes <input type="radio"/> No
7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves? <input type="radio"/> Yes <input checked="" type="radio"/> No <i>Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.</i>
8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales? <input type="radio"/> Yes <input checked="" type="radio"/> No
9. Is the study or any part of it being undertaken as an educational project? <input checked="" type="radio"/> Yes <input type="radio"/> No Please describe briefly the involvement of the student(s): The student will help to collect the data at time point one (pre-intervention) and will subsequently help to analyse this baseline data.

Notice of Amendment

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9a. Is the project being undertaken in part fulfillment of a PhD or other doctorate?
 Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?
 Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?
 Yes No

Notice of Amendment

IRAS Version 3.5

NOTICE OF SUBSTANTIAL AMENDMENT
Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTM/PIs). The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:	
Title	Forename/initials Surname
	Dr Jessica Eade
Work Address	Psychology Services, Hergest Unit Ysbyty Gwynedd Bangor, Gwynedd
PostCode	LL57 2PW
Email	Jessica.Eade@wales.nhs.uk
Telephone	01248384121
Fax	

Full title of study:	Exploring the Effectiveness of the Societies Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study
Lead sponsor:	School of Psychology, Bangor University
Name of REC:	North Wales REC - West
REC reference number:	14/WA0064
Name of lead R&D office:	
Date study commenced:	14th April 2014
Protocol reference (if applicable), current version and date:	Protocol Version 3 17/12/2013
Amendment number and date:	Amendment 1 25/09/2014

Type of amendment
(a) Amendment to information previously given in IRAS <input checked="" type="radio"/> Yes <input type="radio"/> No If yes, please refer to relevant sections of IRAS in the "summary of changes" below.
(b) Amendment to the protocol <input type="radio"/> Yes <input checked="" type="radio"/> No If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.
(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting

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147525/675609/13/811/33774

Notice of Amendment

IRAS Version 3.5

documentation for the study

 Yes No*If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.*

Is this a modified version of an amendment previously notified and not approved?

 Yes No**Summary of changes***Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.**If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.**If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.*

Amendment 1) We would like to contact the participants who took part in the Socialeyes Feasibility Study, and ask them if we can access their University files about their ASD diagnosis. The university already has this information. This is in order to verify the participant's diagnoses of an ASD and when they received their diagnosis. The purpose of this would be to collect data around the type of assessment that they received when being assessed for ASD. This is important for the research to verify that the participants do in fact have ASD. All participants will have submitted this information to the University in order to receive support from the University's Student Support Service.

In the unlikely event that the information in the participant's University file is not sufficient (e.g. not enough detail on what kind of assessment they received) we would like to ask the participants to provide a copy of their ASD assessment report. Consent will be sought and the consent form for supplementary information is attached (V1 26/09/14).

All this additional information will be stored in the same manner as the data previously collected.

Amendment 2) We would like to extend the period of data collection from 31/10/2014 to 31/01/2015. As a result of the successful implementation of Socialeyes at Bangor University, the student support service are going to deliver this programme on a rolling weekly basis as part of their core support for University students with ASD. This will be facilitated by the same individuals who ran the Socialeyes Intervention for the purposes of the Feasibility Study. We would like to continue to collect data on students entering this Socialeyes programme, but this will be pared down from the amount of data collected for the original study. Consent will be sought as per the protocol as the original approved study, but we will also be seeking consent to access details of their ASD diagnosis as detailed in Amendment 1 (see above).

- a) Pre- and post questionnaires (using the same measures as the original study). Given immediately before the participant has their first session of Socialeyes (baseline) and 8-10 weeks post baseline, and 3 months thereafter.
- b) Qualitative interviews after the intervention. These will follow the same schedule as outlined in the previous study, and ask participant how they found socialeyes, what they liked and what they feel could be improved.
- c) In line with the original study, participants will be asked to identify an informant (e.g. parent, friend, or university mentor) and supply their contact details (with the prior permission of the informant). They will be then sent a questionnaire and consent form and asked to completed it and return with a free-post return envelope.

Amendment 3) Due to some participants difficulties in verbal communication, we would like to offer the qualitative interviews via email, as well as continue to offer them face-to-face interviews. The method of communication would be entirely up to the participant, and the interview schedule would be the same as for the face-to-face interviews.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

Notice of Amendment

IRAS Version 3.5

List of enclosed documents		
Document	Version	Date
Consent form for supplementary information	1	26/09/2014
Consent form participant	2	26/09/2014
Information sheet informant	3	26/09/2014
Information sheet participant	6	26/09/2014
Invitation letter informant	3	26/09/2014
Invitation letter participant	3	26/09/2014
Supplementary information request form	1	26/09/2014

Declaration by Chief Investigator

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.*
- I consider that it would be reasonable for the proposed amendment to be implemented.*

This section was signed electronically by Dr. Jessica Eade on 02/10/2014 16:20.

Job Title/Post: Clinical psychologist
 Organisation: BCUHB
 Email: jessicaeade@hotmail.co.uk

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by Mr Heffn Francis on 02/10/2014 16:00.

Job Title/Post: Psychology School Manager
 Organisation: Bangor University
 Email: h.francis@bangor.ac.uk

North Wales Research Ethics Committee – West: Acknowledgement of documents in compliance with additional conditions

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yrhan o sailieth ymchwil Cymru a arban ni gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofdi Cymdeithiad ac Iechyd, Llywodraeth Cymru



Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone / Facsimile: 01248 - 384.877
Email: Rosetta.Roberts@wales.nhs.uk
Website: www.nres.nhs.uk

Dr Jessica Eade
Clinical Psychologist
Betsi Cadwaladr University Health Board
Psychology Services, Hergest Unit
Ysbyty Gwynedd
Bangor, Gwynedd
LL57 2PW jessica.eade@wales.nhs.uk

16 October 2014

Dear Dr Eade,

Study title: Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study

REC reference: 14/WA/0064

Protocol number: 2013-12205

Amendment number: 1

Amendment date: 26 September 2014

IRAS project ID: 147525

The above amendment was reviewed at the meeting of the Sub-Committee held on 16 October 2014.

Ethical opinion

The Sub-Committee reviewed the amendment and noted that three modifications are proposed to current procedures:

The research team would like to contact the participants who took part in the Socialeyes Feasibility Study, and ask their permission to access their University files about their ASD diagnosis. If the information in the participant's University file is insufficient (e.g. not enough detail on what kind of assessment they received) the team would like to ask the participants to provide a copy of their ASD assessment report.

The team would also like to extend the period of data collection from 31/10/2014 to 31/01/2015, and continue to collect data on students entering this Socialeyes programme.

Qualitative interviews will be conducted both face to face and via email.

On the basis of the submitted documentation the Sub-Committee decided that this amendment raises no ethical issues.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.



Cystheir Cytweithredol Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofdi Cymdeithiad ac Iechyd gan Fwrdd Adfyddu Iechyd Powys
The National Institute for Social Care and Health Research Academic Health Science
Collaboration is hosted by Powys Teaching Health Board



14WA/0064

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Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	1	26 September 2014
Letters of invitation to participant	3	26 September 2014
Letters of invitation to participant [Informant]	3	26 September 2014
Participant Information sheet (PIS)	6	26 September 2014
Participant Information sheet (PIS) [Informant]	3	26 September 2014
Other [Supplementary Information Request Form]	1	26 September 2014
Participant consent form [Supplementary Information]	1	26 September 2014
Participant consent form	2	26 September 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.
No conflicts of interest were declared in relation to this application

R&D approval

All Investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

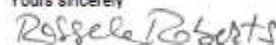
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/WA/0064	Please quote this number on all correspondence
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Yours sincerely



Mr Derek James Crawford, MBChB, FRCS
Chair
E-mail: rossella.roberts@wales.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy: Sponsor: Mr Hefin Francis
School Manager, School of Psychology, Bangor University
Brigantia Building, Penrallt Rd
Bangor, Gwynedd, LL57 2AG h.francis@bangor.ac.uk

Student: Ms Ela Cernyw
NWCPP, School of Psychology
Bangor University
Bangor, Gwynedd, LL57 2DG pspefc@bangor.ac.uk

Academic Supervisor: Dr Mike Jackson
Consultant Clinical Psychologist
BCUHB, Ysbyty Gwynedd
Bangor, Gwynedd LL57 2PW mike.jackson@wales.nhs.uk

14WA/0064

Page 2 of 3

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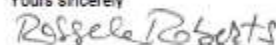
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14/WA/0064	Please quote this number on all correspondence
------------	--

Yours sincerely



Mr Derek James Crawford, MBChB, FRCS
Chair
E-mail: rossella.roberts@wales.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy: Sponsor: Mr Hefin Francis
School Manager, School of Psychology, Bangor University
Brigantia Building, Penrallt Rd
Bangor, Gwynedd, LL57 2AG h.francis@bangor.ac.uk

Student: Ms Ela Cernyw
NWCPP, School of Psychology
Bangor University
Bangor, Gwynedd, LL57 2DG pspefc@bangor.ac.uk

Academic Supervisor: Dr Mike Jackson
Consultant Clinical Psychologist
BCUHB, Ysbyty Gwynedd
Bangor, Gwynedd LL57 2PW mike.jackson@wales.nhs.uk

Wales Research Ethics Committee 5**Attendance at Sub-Committee of the REC meeting on 16 October 2014****Committee Members**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>	<i>Present</i>
Dr. Derek James Crawford	Retired Consultant Surgeon (Chairman)	Expert	Yes
Mr. Eliezer Lichtenstein	Student	Lay +	Yes
Dr Phillip Wayman White	General Practitioner (Vice-Chairman)	Expert	Yes

In attendance

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr. Rossela Roberts	Clinical Governance Officer / RES Manager

Participant Invitation Letter: Cymraeg & English**0/01/14 V2****Llythyr yn gwahodd cyfranogwyr**

Dyddiad: 21/02/14

Annwyl ddarpar gyfranogwr,

**Archwilio effeithiolrwydd ymyriad Socialeyes i ddatblygu sgiliau cyfathrebu a rhyngweithiol
cymdeithasol mewn oedolion gydag anhwylderau ar y sbectrwm awtistig: Astudiaeth
dichonoldeb.**

Rydym yn grŵp o ymchwilwyr sydd wedi eu lleoli yn Ysgol Seicoleg, Prifysgol Bangor a Bwrdd Iechyd Prifysgol Betsi Cadwaladr ac yn cynnal astudiaeth ymchwil am ba mor ddefnyddiol yw rhaglen sgiliau cymdeithasol o'r enw Socialeyes. Cynlluniwyd Socialeyes i bobl gyda chyflyrau sbectrwm awtistig, gan bobl gyda'r cyflwr hwnnw, i helpu cyfranogwyr i ddatblygu eu sgiliau rhyngweithiol a chyfathrebu cymdeithasol.

Bydd cymryd rhan yn yr astudiaeth yn digwydd mewn dwy ran: cymryd rhan mewn rhaglen grŵp Socialeyes am 10 wythnos ac mewn cyfres o gyfweiliadau ymchwil. Cynhelir y rhaglen Socialeyes yn eich coleg neu brifysgol; mae'n rhaglen a gynhelir ar ffurf grwpiau gyda 6-8 aelod ym mhob grŵp. Bydd rhan ymchwil yr astudiaeth yn cynnwys cyfarfod ag ymchwilydd cyn ac ar ôl y rhaglen; a thri mis ar ôl i'r rhaglen orffen, bydd yr ymchwilydd hefyd yn anfon pecyn holiaduron trwy'r post i gyfranogwyr eu llenwi.

Os oes gennych ddi-ddordeb mewn cymryd rhan, darllenwch y daflen wybodaeth amgaeedig yn ofalus, mae croeso i chi ei drafod gyda theulu a ffrindiau cyn penderfynu a ydych am gymryd rhan neu beidio. Os penderfynwch gymryd rhan, llofnodwch y ffurflen gydsynio a'i dychwelyd at hwylusydd Socialeyes (yr unigolyn yn eich coleg neu brifysgol a roddodd y wybodaeth am yr astudiaeth i chi); bydd yr hwylusydd Socialeyes wedyn yn rhoi eich enw i Dr. Bethan Henderson, ymchwilydd arweiniol yr astudiaeth, a fydd yn trefnu cyfarfod â chi.

Os oes gennych unrhyw gwestiynau mae croeso i chi gysylltu â Dr. Jessica Eade trwy e-bost jessicaeade@wales.nhs.uk neu gellwch ei ffonio neu anfon neges destun ar 07541345159 a bydd yn dychwelyd eich galwad cyn gynted ag y bo modd i ateb unrhyw gwestiynau a fydd gennych am yr astudiaeth.

Diolch i chi am ddarllen y llythyr hwn.
Yn gywir,

Dr. Jessica Eade (Seicolegydd Clinigol a Phrif Ymchwilydd)

Ar ran y tîm ymchwil:

Dr. Bethan Henderson (Seicolegydd Clinigol, Ymchwilydd Arweiniol a Chydlynnydd yr Astudiaeth)
Dr. Mike Jackson (Seicolegydd Clinigol Ymgynghorol a Goruchwyliwr Allweddol)
Ms. Ela Cernyw (Seicolegydd Clinigol dan hyfforddiant)
Dr. Gemma Griffiths (Tiwtor Ymchwil, Prifysgol)

9/01/14 V2

Participant Invitation Letter

Date: 21/02/14

Dear Prospective Participant,

Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study.

We are a group of researchers based at the School of Psychology, Bangor University and the Betsi Cadwaladr University Health Board, who are conducting a research study into the usefulness of a social skills programme called Socialeyes. Socialeyes has been designed for and by people with autistic spectrum conditions to help participants develop their social interaction and social communication skills.

Involvement in the study consists of two parts: participation in a 10 week Socialeyes programme group and a set of research interviews. The Socialeyes programme will be run in your college or university; it is a group based programme with 6-8 group members. The research part of the study will involve meeting with a researcher before and after the programme; and, three months after the programme has ended, the researcher will also send out a postal questionnaire pack for participants to complete.

If you are interested in taking part please read the enclosed information sheet carefully, feel free to talk it over with family and friends before deciding whether or not to take part. If you do decide to take part sign the consent form and return it to the Socialeyes facilitator (the person in your college or university who gave you the information about this study); the Socialeyes facilitator will then pass your name to Dr. Bethan Henderson, the lead researcher for the study, who will arrange to meet with you.

If you have any questions please don't hesitate to contact, Dr. Jessica Eade by email on Jessica.eade@wales.nhs.uk or you can phone or send her a text on 07541345159 and she will phone you back as soon as she can to answer any questions that you may have about the study.

Thank you for reading this letter.

Yours sincerely,

Dr. Jessica Eade (Clinical Psychologist and Principal Investigator)

On behalf of the research team:

Dr. Bethan Henderson (Clinical Psychologist, Lead Researcher and Study Co-ordinator)

Dr. Mike Jackson (Consultant Clinical Psychologist and Key Supervisor)

Ms. Ela Cernyw (Trainee Clinical Psychologist)

Dr. Gemma Griffiths (Research Tutor, Bangor University)

Information Sheet participant: Cymraeg & English

9/01/14 V4

Taflen Wybodaeth: Sawl sy'n cymryd rhan

Archwilio effeithiolrwydd ymyriad Socialeyes i ddatblygu sgiliau cyfathrebu a rhyngweithiol cymdeithasol mewn oedolion gydag anhwylderau ar y sbectrwm awtistig: Astudiaeth dichonoldeb.

Diolch i chi am eich diddordeb yn yr astudiaeth ymchwil hon. Cyn i chi benderfynu a hoffech gymryd rhan, mae'n bwysig eich bod yn deall pam mae'r ymchwil yn cael ei wneud a'r hyn y bydd yn ei olygu i chi. Cymerwch amser i ddarllen y wybodaeth ganlynol yn ofalus cyn penderfynu a ydych am gymryd rhan neu beidio. Os oes rhywbeth yn aneglur, neu os hoffech gael mwy o wybodaeth, cysylltwch â'r ymchwilydd arweiniol, Dr. Jessica Eade, naill ai trwy e-bost yn jessica.eade@wales.nhs.uk neu dros y ffôn ar 07541345159. Diolch i chi am ddarllen y daflen hon.

Beth yw diben yr astudiaeth?

Mae Socialeyes yn adnodd dysgu arloesol a ddatblygwyd gan Gymdeithas Genedlaethol Awtistiaeth Cymru a Phrifysgol Cymru, Casnewydd, i gynorthwyo pobl gyda chyflyrau sbectrwm awtistig i ddatblygu eu sgiliau rhyngweithiol a chyfathrebu cymdeithasol. Roedd y tîm datblygu adnoddau yn cynnwys pobl gyda chyflwr sbectrwm awtistig. Fel rheol, caiff y rhaglen Socialeyes ei chyflwyno mewn grwpiau bach. Amcan Socialeyes yw helpu dysgwyr i archwilio'r byd cymdeithasol a bod yn fwy hyderus mewn sefyllfaoedd cymdeithasol. Ni fwriedir iddi fod yn rhaglen hyfforddi sgiliau cymdeithasol o reidrwydd, nid yw'n dweud wrth ddysgwyr sut i newid ymddygiad cymdeithasol "amhriodol". Yn hytrach, y bwriad yw helpu dysgwyr i archwilio rhyngweithio cymdeithasol fel y gallant wneud dewis gwybodus ynglŷn â sut y gallent ymateb mewn sefyllfaoedd tebyg. Er bod Socialeyes wedi'i gymeradwyo gan Gymdeithas Genedlaethol Awtistiaeth ac fe'i defnyddir yn helaeth yn y DU, nid yw wedi cael ei werthuso'n ffurfiol hyd yma. Mae'r astudiaeth hon yn astudiaeth dichonoldeb sy'n archwilio profiad hwyluswyr o gael hyfforddiant a chyflwyno'r rhaglen; a beth yw profiad cyfranogwyr o fod mewn grŵp Socialeyes ac a ydynt yn cael unrhyw fudd ohono neu beidio.

Pam rydw i wedi cael fy newis?

Gofynnwyd ichi gymryd rhan am eich bod wedi cael diagnosis o Gyflwr Sbectrwm Awtistig ac efallai bod gennych ddiddordeb mewn archwilio a datblygu eich sgiliau rhyngweithio cymdeithasol.

Oes rhaid i mi gymryd rhan?

Chi sydd i benderfynu a yw'r astudiaeth ymchwil hon a chymryd rhan mewn grŵp Socialeyes yn addas i chi. Bydd y grŵp yn cyfarfod am 2 awr bob wythnos am 10 wythnos. Mae cymryd rhan yn yr ymchwil a'r gwaith grŵp yn gwbl wirfoddol. Os ydych yn penderfynu cymryd rhan gellwch gadw'r daflen wybodaeth hon, ond rhaid i chi lofnodi'r ffurflen gydsynio sydd yn y pecyn hwn a'i dychwelyd i'ch hwylusydd Socialeyes (yr unigolyn a roddodd y daflen wybodaeth hon i chi). Bydd yr hwylusydd Socialeyes yn archebu lle i chi ar y grŵp Socialeyes yn eich coleg neu brifysgol ac yn rhoi eich manylion cyswllt i'r ymchwilydd arweiniol, Dr. Bethan Henderson, a fydd yn cysylltu â chi. Rydych yn rhydd i dynnu'n ôl o'r ymchwil ar unrhyw adeg a dal i fynd i'r grŵp wythnosol. Neu os penderfynwch nad yw hyn yn addas i chi, gellwch dynnu'n ôl o'r ymchwil a'r grŵp. Os penderfynwch dynnu'n ôl o unrhyw ran o'r astudiaeth nid oes rhaid i chi roi rheswm.

Beth fydd yn digwydd i mi os byddaf yn cymryd rhan?

Os penderfynwch yr hoffech gymryd rhan, dywedwch wrth eich hwylusydd Socialeyes (yr unigolyn a roddodd y daflen wybodaeth hon i chi) a rhoi'r ffurflen gydsynio wedi'i llofnodi iddo/iddi (sydd yn y

pecyn) i'r hwylusydd. Bydd lle yn cael ei gadw i chi ar y grŵp Socialeyes a rhoddir eich enw a'r ffurflen gydsynio i Dr Bethan Henderson, yr ymchwilydd sy'n arwain yr astudiaeth a fydd yn cysylltu â chi i drefnu dyddiad ac amser i'r cyfweiliad sy'n gyfleus i chi.

Pan fydd Bethan yn cysylltu â chi i drefnu dyddiad i'r cyfweiliad, bydd hefyd yn gofyn am enw a manylion cyswllt rhywun sy'n eich adnabod yn dda. Gall yr unigolyn hwn fod yn ffrind, aelod o'r teulu, tiwtor neu fentor cefnogi. Byddwn yn gofyn i'r unigolyn hwn lenwi holiadur byr am eich ffordd o ryngweithio'n gymdeithasol. Ceisiwch ddewis rhywun a fydd yn rhoi sylwadau gwir a gonest am eich ymddygiad cymdeithasol. Byddwn yn gofyn iddynt lenwi'r holiadur hwn dair gwaith: cyn y grŵp Socialeyes, ar ôl y gwaith grŵp a thri mis wedyn. Byddant yn derbyn yr holiaduron trwy'r post.

Yn eich cyfweiliad, byddwn yn gofyn i chi lenwi rhai holiaduron a siarad am sut ydych chi'n teimlo wrth ymweud â phobl eraill a beth yw eich disgwyliadau o gymryd rhan mewn grŵp Socialeyes. Bydd y cyfweiliad hwn yn cael ei recordio ar fideo fel y gallwn gasglu data am eich ffordd o ryngweithio'n gymdeithasol; dim ond aelodau'r tîm ymchwil fydd yn gweld y fideo. Bydd y cyfweiliad a'r holiaduron yn cymryd tuag awr.

Wedyn cewch wahoddiad i gymryd rhan mewn grŵp Socialeyes am 10 wythnos gyda 5 o bobl eraill. Hwylusydd y grŵp yw'r sawl a gyflwynodd yr astudiaeth ymchwil i chi. Bydd y grŵp yn cyfarfod bob wythnos am hyd at 2 awr. Dyma rai o'r dulliau fydd yn cael eu defnyddio: modelu trwy fideo, modelu (trwy hwyluswyr), taflenni gwaith i ymarfer gartref a thrafodaeth grŵp. Rydym yn eich annog i ymarfer rhwng sesiynau; gall hyn gynnwys llenwi taflenni gwaith neu weithio ar sgil gymdeithasol penodol. Mae'n bwysig eich bod yn gwneud eich gorau i fod yn bresennol bob wythnos.

Ar ddiwedd y gwaith grŵp Socialeyes 10 wythnos, bydd Bethan yn cwrdd â chi eto i gael cyfweiliad ar ôl i'r gwaith grŵp ddod i ben, lle bydd yn gofyn i chi lenwi rhai holiaduron a siarad am eich profiad o fod mewn grŵp Socialeyes. Bydd y cyfweiliad hwn hefyd yn cael ei recordio ar fideo fel y gallwn gasglu data am eich ffordd o ryngweithio'n gymdeithasol; dim ond aelodau'r tîm ymchwil fydd yn gweld y fideo. Bydd y cyfweiliad a'r holiaduron yn cymryd tuag awr.

Yn olaf, byddwn yn cysylltu â chi eto ymhen 3 mis ar ôl i'r gwaith grŵp ddod i ben ac yn gofyn i chi lenwi pecyn arall o holiaduron. Bydd hyn yn cymryd tua hanner awr. Gellir gwneud hyn drwy'r post os bydd yn fwy cyfleus i chi.

Beth yw'r anfantaision a'r risgiau posibl o gymryd rhan?

Efallai y byddwch yn teimlo'n anghyfforddus ynglŷn â chwrdd â'r ymchwilydd am y tro cyntaf ac ateb ei chwestiynau. Efallai hefyd y byddwch yn teimlo'n anghyfforddus am gael eich ffilmio yn ystod y cyfweiliad. Ond sylwch y cynhelir yr asesiad yn rhywle sy'n gyfarwydd i chi ac os dymunwch, gallwch ddod â ffrind gyda chi i'ch cefnogi. Efallai bydd cael eich ffilmio braidd yn anodd i ddechrau ond fe welwch eich bod yn cyfarwyddo â'r syniad ac yn anghofio am y camera fideo. Cedwir ein holl ddata'n ddiogel. Dim ond aelodau'r tîm ymchwil fydd yn gweld y recordiadau fideo. Cofiwch, gellwch hefyd drafod eich pryderon gyda Bethan, yr ymchwilydd, ar unrhyw adeg.

Yn ystod y sesiynau grŵp Socialeyes, anogir cyfranogwyr i gymryd rhan mewn trafodaethau grŵp ac efallai nag ydych yn gyfforddus gyda hyn ac mae meddwl am y peth yn gwneud ichi deimlo'n bryderus. Ond cofiwch, nid oes raid i chi siarad os nad ydych eisiau ac ni fyddwch o dan unrhyw bwysau i wneud hynny.

Bydd eich grŵp yn cynnwys tua 5 o bobl eraill y byddwch efallai yn eu hadnabod neu maent yn fyfyrwyr yn eich prifysgol neu goleg. Dylech gofio bod y myfyrwyr hyn i gyd wedi cael diagnosis o Gyflwr Sbectrwm Awtistig a gan eich bod yn aelod o'r grŵp, byddant yn gwybod eich bod chi wedi cael yr un diagnosis hefyd. Os nad ydych eisiau i bobl eraill wybod bod gennych gyflwr sbectrwm awtistig, efallai na fyddwch eisiau cymryd rhan yn y grŵp hwn. Ond ar ddechrau'r grŵp, bydd y

rheolau sylfaenol yn cael eu trafod a bod angen parchu eich gilydd a bydd peidio â siarad am eich gilydd tu allan i'r grŵp yn rheol bwysig.

Beth yw'r manteision posib o gymryd rhan?

Ni allwn addo y bydd cymryd rhan yn y grŵp Socialeyes yn eich helpu. Ond gobeithiwn y cewch brofiad cadarnhaol a chyfle i ddatblygu eich sgiliau cymdeithasol a hyder cymdeithasol. Hefyd, bydd y wybodaeth a gawn o'r astudiaeth yn helpu i wella'r gwaith o gyflwyno grwpiau Socialeyes yn lleol a helpu i wella'r gwasanaethau sydd ar gael i bobl gydag anawsterau rhyngweithio a chyfathrebu'n gymdeithasol.

Beth os bydd problem yn codi?

Os byddwch yn bryderus ynglŷn ag unrhyw agwedd ar yr ymchwil hwn, dylech ofyn am gael siarad â Dr. Bethan Henderson, Cydlynnydd Ymchwil (manyllion cyswllt) neu Dr. Jessica Eade, Prif Ymchwilydd (manyllion cyswllt), a fydd yn gwneud eu gorau i ateb unrhyw gwestiynau.

Os ydych yn dal yn anhapus ac eisiau cwyno'n ffurfiol, gellwch wneud hynny drwy gysylltu â naill ai:

- Adran Cwynion, Bwrdd Iechyd Prifysgol Betsi Cadwaladr, Ysbyty Gwynedd, Bangor, Gwynedd, LL57 2PW
E-bost: complimentsandcomplaints.bcu@wales.nhs.uk
neu
- Hefin Francis, Rheolwr yr Ysgol Seicoleg, Prifysgol Bangor, Bangor, Gwynedd, LL57 2DG
E-bost: h.francis@bangor.ac.uk

A fydd y ffaith fy mod wedi cymryd rhan yn yr astudiaeth yn cael ei chadw'n gyfrinachol?

Caiff holl ddata'r holiaduron eu cadw'n gyfrinachol a'u cloi mewn cwpwrdd ffeilio yn Ysbyty Gwynedd. Rhoddir rhif astudiaeth ar bob holiadur felly bydd eich atebion yn ddiennw. Caiff yr holl ddata ymchwil eu cadw am bum mlynedd cyn cael eu dinistrio.

Yn y cyfweiliad ymchwil caiff holl fanylion personol a recordiadau cyfweiliadau eu trin yn gyfrinachol a'u cadw'n ddiogel. Byddwch yn cael eich enwi wrth eich enw cyntaf yn unig yn ystod y cyfweiliad a bydd unrhyw ddata a gyhoeddir yn ddiennw yn unol â Deddf Diogelu Data 1998. Bydd y cyfweiliadau'n cael eu recordio ar dâp sain i godio a thrawsgrifio data. Bydd y data wedi'u codio yn cael eu hadnabod yn ôl rhif astudiaeth y rhai sy'n cymryd rhan felly bydd eich atebion yn ddiennw. Bydd pob cyfranogwr yn cael ffugenw adeg trawsgrifio'r recordiadau; defnyddir hwn yn yr holl ddogfennau trwy gydol yr astudiaeth. Caiff recordiadau fideo eu dinistrio unwaith y bydd y codio a'r trawsgrifio wedi'u gorffen. Ar ôl i'r astudiaeth gael ei gorffen, cedwir manylion personol am hyd at flwyddyn mewn cwpwrdd ffeilio wedi'i gloi yn Ysbyty Gwynedd. Bydd gweddill y data ymchwil yn cael eu cadw am bum mlynedd cyn cael eu dinistrio.

Beth fydd yn digwydd os nad ydw i am gario ymlaen â'r astudiaeth?

Gellwch dynnu'n ôl o'r astudiaeth unrhyw bryd. Os penderfynwch dynnu'n ôl o'r astudiaeth, cewch barhau i gymryd rhan yn y gwaith grŵp Socialeyes 10 wythnos. Os byddwch yn tynnu'n ôl o'r astudiaeth, byddwn yn dinistrio'ch holl gyfweiliadau ar recordiadau fideo, ond bydd angen i ni ddefnyddio'r data a gasglwyd hyd nes i chi dynnu'n ôl.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth ymchwil?

Ar ddiwedd yr astudiaeth byddwn yn llunio adroddiad adborth a'i anfon atoch. Defnyddir canlyniadau'r astudiaeth hon i'n helpu i wneud cais i gynnal astudiaeth ar raddfa fwy yn archwilio'n fanylach pa mor ddefnyddiol yw'r rhaglen grwpiau Socialeyes. Ni fyddwn yn eich enwi mewn unrhyw adroddiad na chyhoeddiad.

Pwy sy'n trefnu neu'n noddi'r ymchwil?

Prif Ymchwilydd yr astudiaeth hon yw Dr. Jessica Eade (Seicolegydd Clinigol). Dr. Bethan Henderson (Seicolegydd Clinigol) yw Ymchwilydd Arweiniol a Chydlynnydd Astudiaeth y tîm. Dr. Mike Jackson (Seicolegydd Clinigol Ymgynghorol) yw'r Goruchwyliwr Allweddol. Dyma aelodau eraill y tîm ymchwil: Ms. Ela Cernyw (Seicolegydd Clinigol dan hyfforddiant); a, Dr. Gemma Griffiths (Tiwtor Ymchwil). Noddir yr ymchwil gan Ysgol Seicoleg, Prifysgol Bangor a'i ariannu gan gyllid Portffolio Ymchwil a Datblygu Bwrdd Iechyd Prifysgol Betsi Cadwaladr.

Pwy sydd wedi adolygu'r astudiaeth?

Mae'r Ysgol Seicoleg, Pwyllgor Moeseg Ymchwil Prifysgol Bangor wedi adolygu'r astudiaeth hon ac wedi cytuno iddi gael ei chynnal (rhif cyfeirnod: 2013-12205) a Pwyllgor Moeseg Ymchwil Gogledd Cymru - Y Orllewin (rhif cyfeirnod: 14/WA/0064).

9/01/14 V4

Information Sheet: Participant

Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study.

Thank you for your interest in this research study. Before deciding if you would like to take part, you need to understand why the research is being done and how you would be involved. Please take some time to read the following information carefully before deciding whether or not to take part. If there is anything that is not clear, or if you would like more information, please contact the Principal Investigator, Dr Jessica Eade, either by email at Jessica.eade@wales.nhs.uk or by phone on 07541345159. Thank you for reading this.

What is the study about?

Socialeyes is an innovative learning resource developed by the National Autistic Society (NAS) Cymru and University of Wales, Newport, to assist people with Autism Spectrum Condition's (ASC's) to develop their social interaction and communication skills. The resource development team included people with an ASC. The Socialeyes programme is typically delivered in a small group format. The aim of Socialeyes is to help learners explore the social world and become more confident in social situations. It has not been designed as a social skills training programme per se in that it does not tell learners how to change "inappropriate" social behaviour. Rather, it has been designed to help learners explore social interaction so that they can make an informed choice about how they might respond in similar situations. Although Socialeyes is endorsed by NAS and is widely used in the UK, to-date it has not been formally evaluated. This study is a feasibility study exploring how facilitators experience training and delivering the programme; and, how participants experience being in a Socialeyes group and whether or not they get any benefit from it.

Why have I been chosen?

You have been asked to take part because you have a diagnosed Autism Spectrum Condition (ASC) and you may be interested in exploring and developing your social interaction skills.

Do I have to take part?

It is up to you to decide if this research study and participation in a Socialeyes group is for you. The group will run for up to 2 hours per week for 10 weeks. Taking part in the research and the group is voluntary. If you decide to take part you can keep this information sheet, but we need you to sign the consent form that is included in this pack and it return to your Socialeyes facilitator (the person who

gave you this information sheet). The Socialeyes facilitator will then reserve you a place on the Socialeyes group in your college or university and pass your contact details to the lead researcher, Dr. Bethan Henderson, who will get in touch with you. You are free to withdraw from the research at any time and still attend the weekly group. Or, if you decide that this really is not for you, withdraw from the research and the group. If you decide to withdraw from any part of the study you do not need to give a reason.

What will happen to me if I take part?

If you decide that you would like to take part please tell your Socialeyes facilitator (the person who gave you this information sheet) and give them with your signed consent form (contained in this pack), a place will then be reserved for you on the Socialeyes group and your name and consent form will be given to Dr Bethan Henderson the researcher involved in the study who will contact you to arrange an interview date and a time to suit you.

When Bethan contacts you to arrange an interview date, she will also ask you to give her the name and contact details of someone who you feel knows you well. This person can be a friend, family member, tutor or support mentor. This person will be asked to complete a short questionnaire about your social interaction style. Try to pick someone who you feel will give a true and honest representation of your social behaviour. They will be asked to complete this questionnaire three times: before the Socialeyes group, after the group and at a three month follow-up date. They will receive the questionnaire by post.

At your interview, you will be asked to complete some questionnaires and talk about how things are for you when you interact with other people and what your expectations of taking part in a Socialeyes group might be. This interview will be video recorded so that we can collect data about your social interaction style; the video will only be viewed by the research team. The interview and questionnaires will take about 60 minutes.

You will then be invited to take part in a 10 week Socialeyes group with about 5 other people. The group facilitator is the person who introduced the research study to you.

The group will meet every week for up to 2 hours. Amongst the methods used are video modelling, modelling (by facilitators), home practice work sheets and group discussion. You are encouraged to participate in practice between sessions; this may include filling out work sheets or working on a particular social skill. It is important that you try your best to attend every week.

At the end of the 10 week Socialeyes group, Bethan will meet with you again for a post-group interview where you will be asked to complete some questionnaires and talk about your experience of being in a Socialeyes group. Again, this interview will be video recorded so that we can collect data about your social interaction style; the video will only be viewed by the research team. The interview and questionnaires will take about 60 minutes.

Finally, we will contact you again about 3 months after the end of the group and ask you to fill out a final questionnaire pack. This will take you about 30 minutes. This can be done by post, if this is the most convenient for you.

What are the possible disadvantages and risks of taking part?

You may feel uncomfortable meeting the researcher for the first time and answering her questions. You may also feel uncomfortable being filmed during the interview. However, please be aware that the assessment will take place somewhere known to you and that if you would like, you can bring a friend along to support you. Being filmed can seem daunting at first, however, you will find that you get used to it and soon forget that the video camera is there. All our data is kept securely. Video footage will only be viewed by the research team. Remember, you can also speak to Bethan, the researcher, about your concerns at any time.

During the actual Socialeyes group, participants are encouraged to take part in group discussion and you may find this uncomfortable and the thought of this may make you feel quite anxious. However, please be assured that you do not have to talk if you do not want to and you will not be put under pressure to do so.

Your group will consist of about 5 other people who may be known to you or be students in your university or college. You should think about the fact that these students will all have a diagnosed Autism Spectrum Condition (ASC) and by your inclusion in the group, they will know that you have too. If you do not want other people to know that you have an ASC, you may not want to take part in this group. However, at the start of the group, ground rules will be discussed and the need to respect each other and not talk about each other outside of the group will be an important rule.

What are the possible benefits of taking part?

We cannot promise that being involved in the Socialeyes group will help you. However, we hope that you have a positive experience and the opportunity to develop your social skills and social confidence. In addition, the information that we get from the study will help improve the delivery of Socialeyes groups locally and the services available for people with social interaction and communication difficulties.

What if there is a problem?

If you have a concern about any aspect of this research, you should ask to speak to Dr. Bethan Henderson, Research Co-ordinator (contact details) or Dr. Jessica Eade, Chief Investigator (contact details), who will do their best to answer any questions.

If you remain unhappy and wish to complain formally, you can do this by contacting either:

- Complaints Department, Betsi Cadwaladar University Health Board, Ysbyty Gwynedd, Bangor, Gwynedd, LL57 2PW
Email: complimentsandcomplaints.bcu@wales.nhs.uk

Or

- Hefin Francis, School Manager, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2DG
Email: h.francis@bangor.ac.uk

Will my taking part in the study be kept confidential?

All questionnaire data will be kept confidential and kept securely in a locked filing cabinet at Ysbyty Gwynedd. Each questionnaire will be assigned a study number so your responses will be anonymous. All research data will be stored for five years before being destroyed.

In the research interview all personal details and interview recordings will be treated as confidential and kept securely. You will be identified by your first name only during the interview and any published data will be anonymised in accordance with the Data Protection Act 1998. The interviews will be videotaped to allow for coding and transcription of data. Coded data will be identified by the participants assigned study number so your responses will be anonymous. In addition, all participants will be assigned a pseudonym at the point of transcription of the recordings; this will be used on all documentation throughout the study. Video recordings will be destroyed once coding and transcription is complete. Upon completion of the study, personal details will be stored for up to twelve months in a locked filing cabinet at Ysbyty Gwynedd. The rest of the research data will be stored for five years before being destroyed.

What will happen if I don't carry on with the study?

You can withdraw from the study at any time. If you choose to withdraw from the study, you can continue to participate in the 10-week Socialeyes group. If you withdraw from the study we will destroy all your video recorded interviews, but we will need to use the data collected up to your withdrawal.

What will happen to the results of the research study?

At the end of the study we will produce a feedback report which we will send out to you. The results of this study will be used to inform an application to conduct a larger scale study examining the usefulness of the Socialeyes group programme in more detail. You will not be identified in any report/publication.

Who is organising or sponsoring the research?

The Principal Investigator for this study is Dr. Jessica Eade (Clinical Psychologist). Dr. Bethan Henderson (Clinical Psychologist) is the Lead Researcher and Study Co-ordinator on the team. Dr. Mike Jackson (Consultant Clinical Psychologist) is the Key Supervisor. Other members of the research team are: Ms. Ela Cernyw (Trainee Clinical Psychologist); and, Dr. Gemma Griffiths (Research Tutor). The research is sponsored by the School of Psychology, Bangor University and funded by Research and Development Portfolio funding from the Betsi Cadwaladr University Health Board.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by the School of Psychology (ref: 2013-12205), Bangor University Research Ethics Committee and North Wales Research Ethics Committee – West (ref: 14/WA/0064).

Participant Consent Form: Cymraeg & English

Rhif yr astudiaeth:

9/01/14 V1

Rhif adnabod cyfranogwr ar gyfer yr astudiaeth hon:

FFURFLEN GYDSYNIO'R SAWL SY'N CYMRYD RHAN

Teitl y Project: Archwilio effeithiolrwydd ymyriad Socialeyes i ddatblygu sgiliau cyfathrebu a rhyngweithiol cymdeithasol mewn oedolion gydag anhwylderau ar y sbectrwm awtistig: Astudiaeth dichonoldeb.

Enw'r Ymchwilydd Arweiniol: Dr. Bethan Henderson, Seicolegydd Clinigol, Gwasanaethau Seicoleg, Uned Hergest, Ysbyty Gwynedd, Bangor, Gwynedd LL57 2PW

- | | Llofnodwch y
bocsys |
|---|--------------------------|
| 1. Rwy'n cadarnhau fy mod wedi darllen a deall y daflen wybodaeth i gyfranogwyr dyddiedig..... (fersiwn.....) ar gyfer yr astudiaeth uchod. Rwyf wedi cael cyfle i ystyried y wybodaeth a gofyn cwestiynau ac wedi cael atebion boddhaol. | <input type="checkbox"/> |
| 2. Rwy'n deall fy mod yn cymryd rhan yn wirfoddol ac y gallaf dynnu'n ôl unrhyw bryd, heb roi rheswm a heb i hynny effeithio ar fy hawliau cyfreithiol. | <input type="checkbox"/> |
| 3. Rwy'n cydsynio i'r cyfweiliadau gael eu recordio ar dâp sain a'u trawsgrifio. | <input type="checkbox"/> |
| 4. Deallaf y bydd canlyniadau'r astudiaeth yn cael eu cyhoeddi'n ddienw ac y gall dyfyniadau uniongyrchol o'r cyfweiliad gael eu defnyddio ond ni fydd yn bosib fy adnabod oddi wrthynt. | <input type="checkbox"/> |
| 5. Rwy'n cytuno i gymryd rhan yn yr astudiaeth uchod. | <input type="checkbox"/> |

Enw'r sawl sy'n cymryd rhan Dyddiad

Llofnod

Study Number: 9/01/14 V1
Participant Identification Number for this study:

PARTICIPANT CONSENT FORM

Title of Project: Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study.

Name of Lead Researcher: Dr. Bethan Henderson, Clinical Psychologist, Psychology Services, Hergest Unit, Ysbyty Gwynedd, Bangor, Gwynedd LL57 2PW

Please initial box

1. I confirm that I have read and understand the participant information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.

3. I give my consent for the interviews to be video-taped and transcribed.

4. I understand that the results of the study will be published in anonymous format and that direct quotations from the interview may be used but I will not be identifiable from these.

5. I agree to take part in the above study.

Name of participant

Date

Signature

Participant Invitation Letter: Facilitator

Date:

Dear Prospective Participant,

Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study.

We are a group of researchers based at the School of Psychology, Bangor University and the Betsi Cadwaladr University Health Board, who are conducting a research study into the usefulness of a social skills programme called Socialeyes. Socialeyes has been designed for and by people with autistic spectrum conditions to help participants develop their social interaction and social communication skills.

As you are one of the Socialeyes programme facilitators, we are interested in your experience of training in, and delivering, this programme. We are inviting you to take part in an interview following completion of the Socialeyes programme that you are delivering in the context of the above named study.

If you are interested in taking part in the post-programme interview, please read the enclosed information sheet carefully, feel free to talk it over with family and friends before deciding whether or not to take part. If you do decide to take part sign the consent form and return it to Dr. Bethan Henderson, the lead researcher for the study.

If you have any questions please don't hesitate to contact Dr. Bethan Henderson by email on xxxxxx or you can phone or send her a text on xxxxx and she will phone you back as soon as she can to answer any questions that you may have about the study.

Thank you for reading this letter.
Yours sincerely,

Dr. Jessica Eade (Clinical Psychologist and Principal Investigator)

On behalf of the research team:

Dr. Bethan Henderson (Clinical Psychologist, Lead Researcher and Study Co-ordinator)
Dr. Mike Jackson (Consultant Clinical Psychologist and Key Supervisor)
Ms. Ela Cernyw (Trainee Clinical Psychologist)
Dr. Gemma Griffiths (Research Tutor, Bangor University)

Information Sheet: Facilitator**Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study.**

Thank you for your interest in this research study. Before deciding if you would like to take part, you need to understand why the research is being done and how you would be involved. Please take some time to read the following information carefully before deciding whether or not to take part. If there is anything that is not clear, or if you would like more information, please contact the lead researcher, Dr. Bethan Henderson, either by email at xxxxx or by phone on xxxxx. Thank you for reading this.

What is the study about?

Socialeyes is an innovative learning resource developed by the National Autistic Society (NAS) Cymru and University of Wales, Newport, to assist people with Autism Spectrum Condition's (ASC's) to develop their social interaction and communication skills. The resource development team included people with an ASC. The Socialeyes programme is typically delivered in a small group format. The aim of Socialeyes is to help learners explore the social world and become more confident in social situations. It has not been designed as a social skills training programme per se in that it does not tell learners how to change "inappropriate" social behaviour. Rather, it has been designed to help learners explore social interaction so that they can make an informed choice about how they might respond in similar situations. Although Socialeyes is endorsed by NAS and is widely used in the UK, to-date it has not been formally evaluated. This study is a feasibility study exploring how facilitators experience training and delivering the programme; and, how participants experience being in a Socialeyes group and whether or not they get any benefit from it.

Why have I been chosen?

You have been asked to take part because you are a facilitator for one of the Socialeyes groups that is involved in this research study.

Do I have to take part?

It is up to you to decide if you want to take part in this research; taking part is voluntary. If you decide to take part you can keep this information sheet, but we need you to sign the consent form that is included in this pack and return it to Dr Bethan Henderson in the envelope provided. You can withdraw from the study at any time and if you do, you do not need to give a reason.

What will happen to me if I take part?

If you decide that you would like to take part please sign and return the enclosed consent form to Dr. Bethan Henderson in the envelope provided. At the conclusion of the Socialeyes group that you are facilitating, Bethan will contact you to arrange an interview with you at your convenience.

The interview will be conducted by Dr. Bethan Henderson, it will consist of a semi-structured interview taking approximately 30-45 minutes to complete. The focus of the interview will be

to explore your experience of the Socialeyes training; the utility of the programme material; any issues faced in recruitment and delivery of the programme; and, your perception of the impact of the programme, if any, on your institution and student support services. The interview will be audio-recorded.

What are the possible disadvantages and risks of taking part?

You may feel uncomfortable participating in an interview which is being audio-recorded; however, you will find that as you get into the interview this is not too uncomfortable.

What are the possible benefits of taking part?

The information that you provide will help improve the delivery of Socialeyes groups locally and, in the broader picture of the research study, may help to improve the services available for adults with ASC's.

What if there is a problem?

If you have a concern about any aspect of this research, you should ask to speak to Dr. Bethan Henderson, Research Co-ordinator (contact details) or Dr. Jessica Eade, Chief Investigator (contact details), who will do their best to answer any questions.

If you remain unhappy and wish to complain formally, you can do this by contacting either:

- Complaints Department, Betsi Cadwaladar University Health Board, Ysbyty Gwynedd, Bangor, Gwynedd, LL57 2PW
Email: complimentsandcomplaints.bcu@wales.nhs.uk

Or

- Hefin Francis, School Manager, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2DG
Email: h.francis@bangor.ac.uk

Will my taking part in the study be kept confidential?

If you take part in the research interview all personal details and interview audio-recordings will be treated as confidential and kept securely. You will be identified by your first name only during the interview and any published data will be anonymised in accordance with the Data Protection Act 1998. The interviews will be audiotaped and transcribed. All participants will be assigned a pseudonym at the point of transcription of the recordings. This will be used on all documentation throughout the study. Audio recordings will be destroyed once transcription is complete. Upon completion of the study, personal details will be stored for up to twelve months in a locked filing cabinet at Bangor University. The rest of the research data will be stored for five years before being destroyed.

What will happen if I don't carry on with the study?

You can withdraw from the study at any time and if you do so you do not need to give a reason. If you withdraw from the study we will need to use the data collected up to your withdrawal.

What will happen to the results of the research study?

At the end of the study we will produce a feedback report which we will send out to you. The results of this study will be used to inform an application to conduct a larger scale study examining the usefulness of the Socialeyes group programme in more detail. You will not be identified in any report/publication.

Who is organising or sponsoring the research?

The Principal Investigator for this study is Dr. Jessica Eade (Clinical Psychologist). Dr. Bethan Henderson (Clinical Psychologist) is the Lead Researcher and Study Co-ordinator on the team. Dr. Mike Jackson (Consultant Clinical Psychologist) is the Key Supervisor. Other members of the research team are: Ms. Ela Cernyw (Trainee Clinical Psychologist); and, Dr. Gemma Griffiths (Research Tutor). The research is sponsored by the School of Psychology, Bangor University and funded by Research and Development Portfolio funding from the Betsi Cadwaladr University Health Board.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by the School of Psychology, Bangor University Research Ethics Committee (reference number xxx).

Study Number:
Participant Identification Number for this study:

FACILITATOR CONSENT FORM

Title of Project: Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study.

Name of Lead Researcher: Dr. Bethan Henderson, Clinical Psychologist, Psychology Services, Hergest Unit, Ysbyty Gwynedd, Bangor, Gwynedd LL57 2PW

Please initial box

- 1. I confirm that I have read and understand the participant information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.
- 3. I give my consent for the interviews to be audio-taped and transcribed.
- 4. I understand that the results of the study will be published in anonymous format and that direct quotations from the interview may be used but I will not be identifiable from these.
- 5. I agree to take part in the above study.

Name of facilitator

Date

Signature

Information sheet for participants re: additional information

Study Number: 17/09/14 V1
Participant Identification Number for this study:

Supplementary Information Request Form

Title of Project: Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study.

Name of Lead Researcher: Dr. Jessica Eade, Clinical Psychologist, Psychology Services, Hergest Unit, Ysbyty Gwynedd, Bangor, Gwynedd LL57 2PW

Dear Participant,

Thank you for taking part in the above study. In order for us to confirm your diagnosis of an Autistic Spectrum Condition / Asperger's Syndrome, and to establish how and when you were assessed, with your consent, we would like to access the information you provided to the University Support Service about your diagnosis.

When you registered with Bangor University Student Support you were asked to provide evidence that you had a diagnosis of an Autism Spectrum Disorder. This may have been a letter from your GP or an assessment report from a Clinical Psychologist. We would like to see this information in order to see what kind of Autism Spectrum Disorder assessment you received, and when you were assessed.

In some cases, the information provided to the University may not be enough for us to understand what kind of assessment you received (e.g. could be a short letter from your GP reporting the diagnosis with no additional information about what kind of assessment you received). If this is the case we would like to ask you if we could see your Autism Spectrum Disorder assessment report. All of the information collected will be kept confidential and kept securely in a locked filing cabinet at Ysbyty Gwynedd.

If you are willing for us to see the information in the University file or if you are willing for us to ask to see your assessment report (if necessary) please read and sign the consent form included and return to us in the envelope provided.

Yours sincerely

Dr Jessica Eade

Consent form for participants re: additional information

Study Number: 17/09/14 V1
 Participant Identification Number for this study:

PARTICIPANT CONSENT FORM

Title of Project: Exploring the Effectiveness of the Socialeyes Intervention for Developing Social Communication and Interaction Skills in Adults with Autistic Spectrum Disorders: A Feasibility Study.

Name of Lead Researcher: Dr. Bethan Henderson, Clinical Psychologist, Psychology Services, Hergest Unit, Ysbyty Gwynedd, Bangor, Gwynedd LL57 2PW

Consent to access Autism Spectrum Disorder assessment report

Please initial box

1. I confirm that I have read and understand the participant information sheet dated 17/09/14 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I give my consent for the research team to access the information I provided to the University Student Support service about my diagnosis of Autism Spectrum Disorder.

3. If the information I provided to the University Student Support Service about my diagnosis of Autism Spectrum Disorder is not detailed enough, I give my consent for the research team to contact me to ask for a copy of my Autism Spectrum Disorder assessment report.

4. I understand that the results of the study will be published in anonymous format and that direct information about my assessment will not be identifiable from these.

 Name of participant

 Date

 Signature

General Appendix

Appendix 1 Extract from Individual Transcript

Appendix 2 Extract from Individual Theme Table

Appendix 3: Diagrammatic illustration of themes

Appendix 4 Extract from Master Theme Table

Word count statement

Appendix 1: Extract from Individual Transcript

	INT: Okay, well let's get through this as quickly as we can.	
	RES: Oh it's ... its fine, I'm just ...	
	INT: Yeah, just let ...	
	RES: ... in case ...	
	INT: ... just let me know.	
	RES: ... I suddenly have to go.	
	INT: Okay, that's fine. Alright. So just to start with, I was just wondering what ... what your overall ... how did you find the Socialise Group?	
	RES: I thought it was very, very useful. Erm, because ... erm ... it's made me think a lot about erm ... my ... myself in various situations. So like I always ... I kind of categorise everything, so I like ... it helped me categorise how I behave with ... like in a professional setting, so like ... erm ... school I guess. And erm ... erm ... being in like a working environment, like going to the shop or something, or a pub ...	<p>Positive Very useful Self-reflection Categorise things → behaviour Professional setting School working setting pub</p>
	INT: Okay.	
	RES: ... and ordering a drink. And then ... and then with ... a large group of friends, and then the small group of friends. So that it kind of helped me like	<p>Behaviour More flexible Categories</p>

ALPac

<p>balance out the different rules of each social setting I guess, if that makes sense? It makes sense to me ...</p>	<p>helped to provide cues as to how to behave in different social situations: diff rules for diff settings</p>
<p>INT: Yeah.</p>	
<p>RES: ... but I don't know ...</p>	
<p>INT: So you make ... does it ... I'm just ... if I've got this wrong just tell me. Is it like it's made the kind of ... the sort of rules of ... like explicit for different things, and so those things are ...</p>	<p>made the rules explicit</p>
<p>RES: Erm, it just made them ... a bit ... a bit easier. Like instead of just using one rule for every situation, which is what I'd usually do, I'd usually ... I'd usually be really, really formal in every situation, but now it's kind of like ... showed that you don't have to be so formal in every situation.</p>	<p>Categorically. more flexible Positives Benefits of groups</p>
<p>INT: So you kind of differentiated ...</p>	
<p>RES: Yeah.</p>	
<p>INT: ... how you are kind of thing?</p>	
<p>RES: Yeah.</p>	
<p>INT: Okay.</p>	

RES: If that makes sense?	
INT: Yeah. No that does.	
RES: Like I said, it makes sense to me, but ...	
INT: Yeah. No, no, that makes sense.	
RES: ... bringing it off is a bit difficult.	
INT: Okay.	
RES: And it also erm ... made me erm ... question a lot of things, because I only got my diagnosis a few years ago, like three years ago maybe.	Self reflection hate diagnosis Questioned things
INT: Okay.	
RES: So ... so I hadn't really had that much information given about what Asperger's is, and it didn't really ... I didn't really get much like ... it was just like okay, you have this, and I kind of had to find out the information myself.	Post diagnostic support - lack of - self discovery Autism journey
INT: So how old were you when you got diagnosed?	
RES: Seven ... seventeen ...	hate diagnosis.
INT: Oh okay.	

<p>RES: ... I think. Yeah, seventeen ... seventeen, eighteen ... seventeen; I'm going to say seventeen.</p>	<p>hate diagnosis</p>
<p>INT: Okay.</p>	
<p>RES: And erm ... and so like doing the ... course has kind of made me like ... learn a bit more, and a bit ... and make me feel a bit better about why I do things, and then how to cope with things.</p>	<p>Benefits / outcomes Validated experience Psycho-education Provided info about ASD</p>
<p>INT: Okay.</p>	
<p>RES: If that makes sense?</p>	
<p>INT: So you ... so you kind of got quite a bit of information?</p>	
<p>RES: Yeah.</p>	
<p>INT: Yeah.</p>	
<p>RES: Yeah. Because I think the other guys I was with erm, they'd had their diagnoses when they were quite young, or ... one of them had it quite a few ... not that long ago as well. So it was kind of like ... it was good to see how someone who knew all about it from the beginning, and then myself who kind of ... <u>learned</u> and <u>grappled with things</u>. So it was quite interesting in that sense as well.</p>	<p>Autism journey Fast diagnostic Heard from others Shared experiences "Grappled with things"</p>

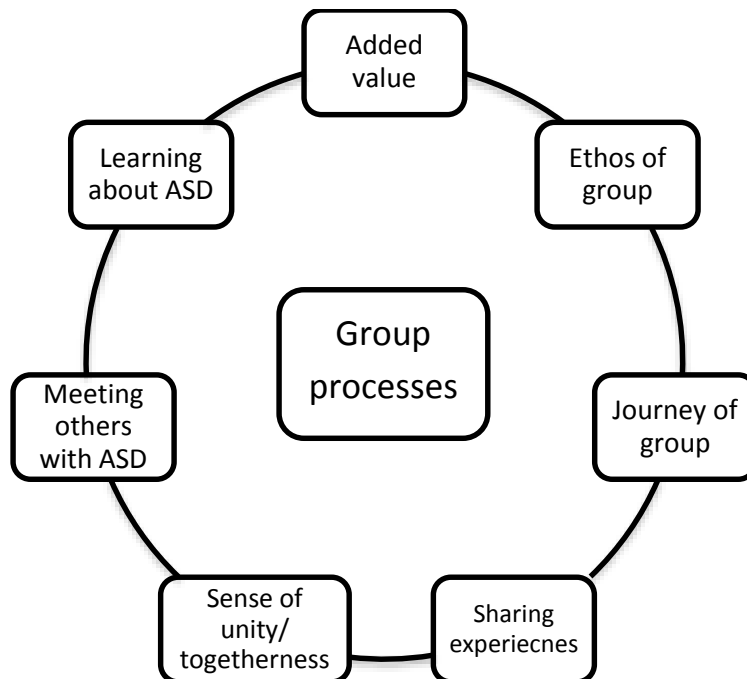
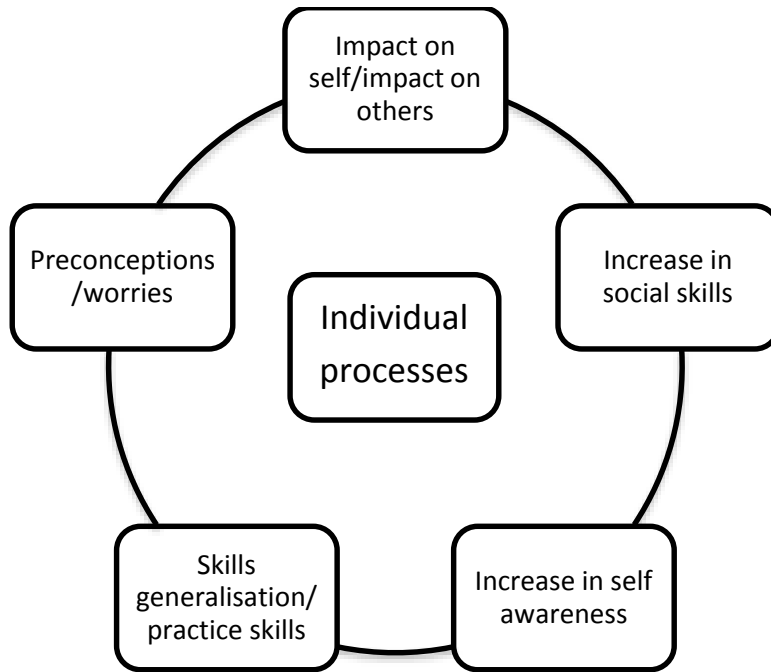
Appendix 2: Extract of individual theme table (S)

<i>Themes/ Subthemes</i>	<i>Paragraph of quote</i>	<i>Quote</i>
Intervention outcomes What was learnt Practice skills outside of group	306	I just really enjoyed it to be honest, it was ... just quite a nice learning experience. And I'd be able to come home and be like ... I think it was ... it was more just of a ... a discovery thing as well as just a learning thing. So, like I'd ... I'd go to my friends and practice my skills, and then ... and then kind of go away and ... then like relay it to the group and then get feedback. And it would be ...
Generalisation of skills	315	I wouldn't ... I'd ... so with my housemates that I'd lived with, that I live with, my two best friends, I'd kind of go 'We did this today', but I wouldn't exactly go 'I'm now going to go and practice what I learnt' ...
Covert practising of skills	318	it was more just, oh ... like retelling what I did in a ... you know, in my literature class, it was just 'Oh, I read this book today', it was a 'Yeah, we did a module on personal space today', and then kind of ... but then like ... I guess like sneakily, not knowing I'm doing it. practice what I'd learnt.
Increase in self awareness Categorising process	85	I thought it was very, very useful. Erm, because ... erm ... it's made me think a lot about erm ... my ... myself in various situations. So like I always ... I kind of categorise everything, so I like ... it helped me categorise how I behave with ... like in a professional setting, so like ... erm ... school I guess. And erm ... erm ... being in like a working environment, like going to the shop or something, or a pub ... and ordering a drink. And then ... and then with ... a large group of friends, and then the small group of friends. So that it kind of helped me like balance out the different rules of each social setting I guess, if that makes sense? It makes sense to me ...
Being more flexible	97	Erm, it just made them ... a bit ... a bit easier. Like instead of just using one rule for every situation, which is what I'd usually do, I'd usually ... I'd usually be really, really formal in every situation, but now it's kind of like ... showed that you don't have to be so formal in every situation.
Improvement in social skills - Not at rude - listening more/more empathic	447	listen ... I listen more to people and kind of ... not be as ... rude as I used to be. Like ... and I'd ... I follow a lot more of the social fixtures that they talk about. Erm ... erm ... I can't really give specific examples, but I just know in myself that I've taken on board quite a lot of ... what the modules have been saying. Erm, like starting a conversation, and ... erm ... knowing how long to talk, and ... erm ... allowing other people to talk and stuff. That was quite a big one, but I hadn't ... I knew about it, but I didn't quite ... think about it. So it's only occasionally

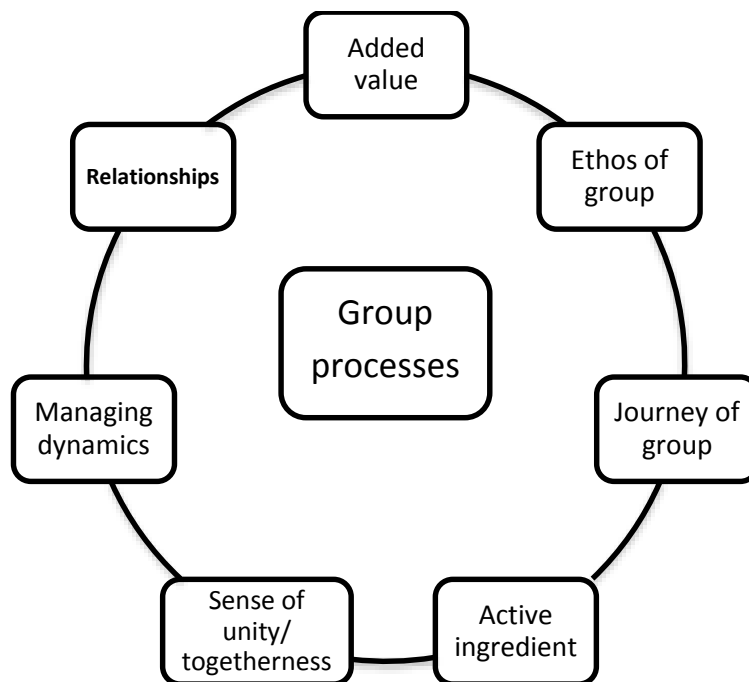
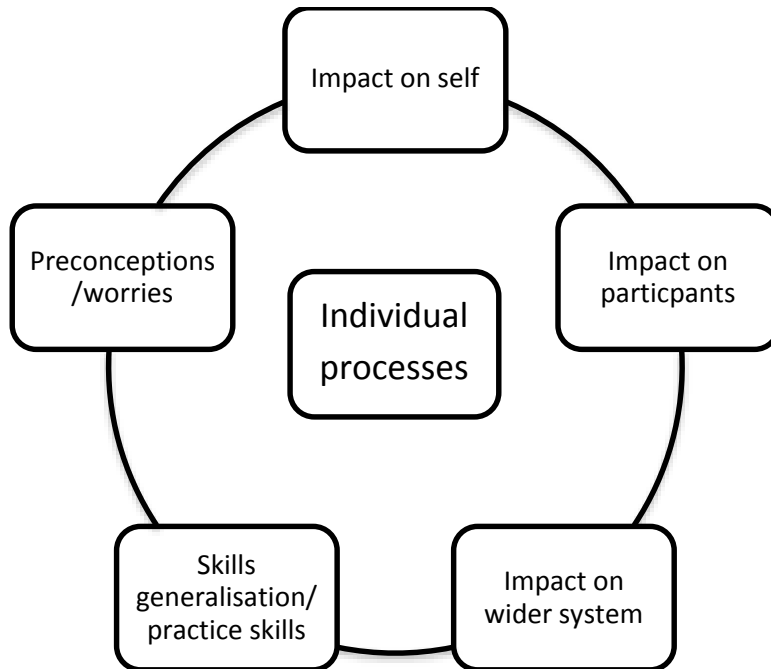
<p>More Sensitive/empathic</p>	<p>459</p>	<p>where my ... closest friends would kind of go ‘Okay, stop now, let someone else have a turn’. But erm ... I ... I think I know more now myself like ... when I’ve ... when I do certain things that I’ve kind of learnt about. But again, I can’t really give too many specific examples, just because it ... its more I know myself ... erm ... that is why it’s helped me. Like, because before I wouldn’t really think about it and now it’s kind of more ... conscious.</p> <p>I still don’t make eye contact erm ... but I think that’s just ... the only one, because ... I ask a lot more questions, like with the sensitive topics one especially, I ... I prompt myself more. But I used to kind of do it anyway, but I’ve found myself doing it more, with ‘Do you mind if I ask ...?’, or ... erm ... I kind of just sort of wheedle my way through a bit more with certain situations. So it’s quite ... helpful.</p>
<p>Group based processes/ Added value of group</p> <p>Meeting others with ASD</p> <p>Opportunity to discuss similar experiences</p>	<p>296</p>	<p>Err ... on a ... hmm; on a personal level, it was just err ... a) meeting other people with the same condition, that was a good thing, but b), on another personal issue, err ... more like ... it was just very, very helpful, like with erm ... especially the eye contact one, they said erm ... we had a lot of discussions on that. Erm, so it’s kind of helped me realise when I am or when I’m not using eye contact, and it prompted a lot of ... discussion and ... so it really kind of made ... instead of just sort of brushing it aside, it really kind of made you think and made you like practice certain things.</p>
<p>Sharing experiences</p> <p>Validating each others experiences</p> <p>Non-judgmental ethos</p> <p>Accepting environment</p>	<p>327</p> <p>406</p>	<p>Because like if ... because quite a few of us shared quite a lot of personal stories, like erm ... err, like going back to the eye contact one, because that’s the one I remember most. Erm, err ... I ... I shared a story where a ... a girl in high school used to make me like ... she would move herself so I’d have to be physically making eye contact with her.</p> <p>And they ... everyone kind of in the group said well that’s ... that’s really mean and that’s ... that’s not very good. And then someone else would share another similar personal story, and so you kind of couldn’t go ‘Oh well, we had a great story today, blah, blah, blah, blah, blah’, you know ...</p> <p>I’m ... I’m quite ... again, I think that’s a personal thing, I quite like hearing what other people think, but I think that’s just because ... it’s all still very new to me. Erm ...</p>
<p>Pressure to contribute</p> <p>Group dynamics</p> <p>Numbers</p>	<p>224</p>	<p>Erm, because it was a very small group, I think there were four of us ... yeah about four of us, that was quite ... err, on the one hand it was quite good that it was so small, but then on the other hand it was kind of ... because me and this other guy were the only ones that really spoke, so it kind of felt a bit like ... someone else say something (whispering).”</p>

Appendix 3: Diagrammatic illustration of participants and facilitators' themes

Participants



Facilitators



Appendix 4: Extract from Master Theme Table (after combining participant and facilitator main theme tables)

Line number	Name	Quote
Theme- <i>Where people were at/preconceptions/worries</i>		
PARTICIPANTS		
54	B	Err ... erm ... meeting new people and ... trying to contribute to the group.
9	J	Yeah, it was ... better than I expected. I thought it was going to be a bit lame and that nobody was going to say anything. Because ... what exactly do you hope to get out of a bunch of socially awkward people when you throw them in a room together and tell them to ...socialise?
81	J	A little bit, but I just kind of gave myself a talking to. Just sort of said 'Look, you're probably going to be the oldest person in there, at least amongst the students, get a grip'.
488	S	Erm ... it's going to sound bad when I say I didn't have that many expectations, I was more going along for the ... let's see what this kind of a thing. Like I didn't really have 'I want to know about this and I'm going to make sure I get it', it was more just a 'This is kind of interesting, this could help, let's see what happens'. Erm ... so ...
23	T	"I was expecting eight people so when I saw four people I felt a bit more confident, because large groups I'm not that keen on."
FACILITATORS		
221	G	and ... you kind of worry, gosh, you know, are they actually going to talk to each other or is it just going to be ... a bunch of silence, but they talked a lot; I think it's because they felt more comfortable with each other at those later stages.
272	E	And also just I think I've got more confident in terms of ... I was quite ... I was quite nervous running that group to start with, just thinking ... because everybody's got so many different social difficulties, I was thinking 'Is this just going to be really painful and difficult?', and I ... you know, so I was nervous, but I ... it ... it worked well, and I've got more confident, so I suppose I feel it gave me ... it boosted my confidence as well ...
459	E	It was only sort of reflecting back that I realised I'd been a bit worried about there being a difficult situation. And that, again, might just be a happy co ... you know, lucky. But ... I was worried I think that somebody would get upset or anxious, or into an argument or something in a session, and that ... we didn't have anything like that, so that was good.
462	E	And erm ... we ... what we didn't have, which I was a bit surprised about and very pleased about, we didn't have any ... issues with participants doing anything

306	E	<p>inappropriate, or anybody feeling challenged or uncomfortable, or anything like that. I think that ... although I maybe hadn't ... clearly recognised that before I started; I think that was one of my concerns, and when that didn't happen that ... was really positive.</p> <p>Because I suppose I had this nagging fear that actually they weren't going to find it useful, or they were going to feel it as a pressure to come, or that they ought to come, just a kind of obligation.</p>
Theme- <i>Ethos of the group/ group environment</i>		
PARTICIPANTS		
337	J	But in a situation where everybody in the group is feeling exactly the same. Everybody in the group has the same problems. Everybody in the group is in the same boat. It makes it a lot easier to keep your nerve when you know that ... okay, everyone here is feeling just as nervous as I am; I don't need to be nervous.
327	S	Because like if ... because quite a few of us shared quite a lot of personal stories, like erm ... err, like going back to the eye contact one, because that's the one I remember most. Erm, err ... I ... I shared a story where a ... a girl in high school used to make me like ... she would move herself so I'd have to be physically making eye contact with her.
406	S	And they ... everyone kind of in the group said well that's ... that's really mean and that's ... that's not very good. And then someone else would share another similar personal story, and so you kind of couldn't go 'Oh well, we had a great story today, blah, blah, blah, blah, blah', you know ...
	T	Being with people who had similar experiences to what I had in the past was actually helpful ... it was friendly, I could speak my own mind.... and I was glad that everyone else was able to not judge me
FACILITATORS		
475	E	So an incredibly personal thing is happening in a group situation. There's something about the group that enabled ...But you kind of would think it would be easier in a one to one ... but ironically it was easier in a group, In a group that was specifically about those issues so it gave you a ... gave me a framework to be able to talk about those things, and for them to ask questions.
210	E	Yeah. Overall it was very positive. I really enjoyed it. Erm ... I felt like I learned a lot. And ... erm ... I think ... we created a safe space, which was really good,
658	E	It was useful to have ... you know, that this programme is for people with Asperger's, and is for ... for Autistic Spectrum Conditions, and has been developed by people, so it was a given that these might be issues for people, rather than having to kind of ... I don't know, it's hard to ... not ... not tread

		carefully but, you know, because it was a given that we were there talking about some of these things, that kind of made it easier for people to open up I think.
646	E	A lot of it is to do with just giving people that opportunity to be able to talk about how they feel, and how difficult they find these things together, that seemed to be a really valuable thing for them...and I think we created a safe space, which was really good.
153	G	But erm ... that seemed to be a really valuable thing for them, just to be able to say 'Gosh', you know, 'I ... I find eye contact difficult'. And they all found things difficult in different ways.
155	G	so it wasn't just ... it was a shared experience but it was also a varied experience within that group. So ... yeah, that was ... that ... you know, I genuinely liked the feeling ... tone of it was that I just found it very rewarding. And err, I suppose like the ... you know, apart from the difficulties of the materials, and I think we would, you know, if we did it again I think we'd be so much better ...
464	G	I'd say, you know, people are quite vulnerable when they come to the programme so be really ... it's really important to make them feel welcome and to not pressure anyone to do something that they don't feel comfortable doing. If people want to turn up and sit in silence, and I think in fact we said that the first day, if you just sit in silence and just listen, that's absolutely fine to do. So there's something about accepting everyone for ... for where they are, and who they are and what they have to contribute. I think the feeling tone is much more ... yeah, I would be keen to emphasise the feeling tone of the group, making people want to join, you know, it's a club where they ... they belong to. Erm, and then the ... the kind of programme is quite obvious, it just falls into place I think, but I think the feeling tone has to be really positive, really validating, and really accepting. Erm, and that's the thing I would probably want to emphasise. And then the ... the teaching ... comes alongside that ... that naturally. Yeah, I suppose its remembering what the intention is really; the intention is to teach social skills, but also ... to help people with their confidence. We've got it all today haven't we (laughs).

Word Count Statement

Thesis Component	Word Count
Title	6
Thesis Abstract	269
Literature Review	5899
Literature Review Figure	84
Literature Review Table	1673
Literature Review References	1058
Empirical Paper	6929
Empirical Paper Tables	180
Empirical Paper References	827
Contributions to Theory and Clinical Practice	4816
Contributions to Theory and Clinical Practice references	966
Word count excluding tables, figures, reference lists and appendices	<u>17,919</u>
Appendices	
Empirical Paper Appendix C	193
Empirical Paper Appendix D	265
Empirical Paper Appendix E	225
Section 5: Ethics Appendices	
Confirmation of School of Psychology Ethical Approval	254
Participant Invitation Letter: Cymraeg & English	738
Information Sheet participant: Cymraeg & English	3871

Participant Consent Form: Cymraeg & English	388
Facilitator Invitation Letter	305
Information Sheet facilitator	1098
Facilitator Consent Form	187
Information sheer: Additional information	324
Consent form for additional information	224
Section 6: General Appendices	
Extract from interview transcript	905
Extract from individual theme table	1148
Diagrammatic illustration	81
Extract from master theme table	1428
Appendices including figures, tables and reference lists, excluding ethics appendix	<u>9033</u>
Total word count	<u>26,952</u>