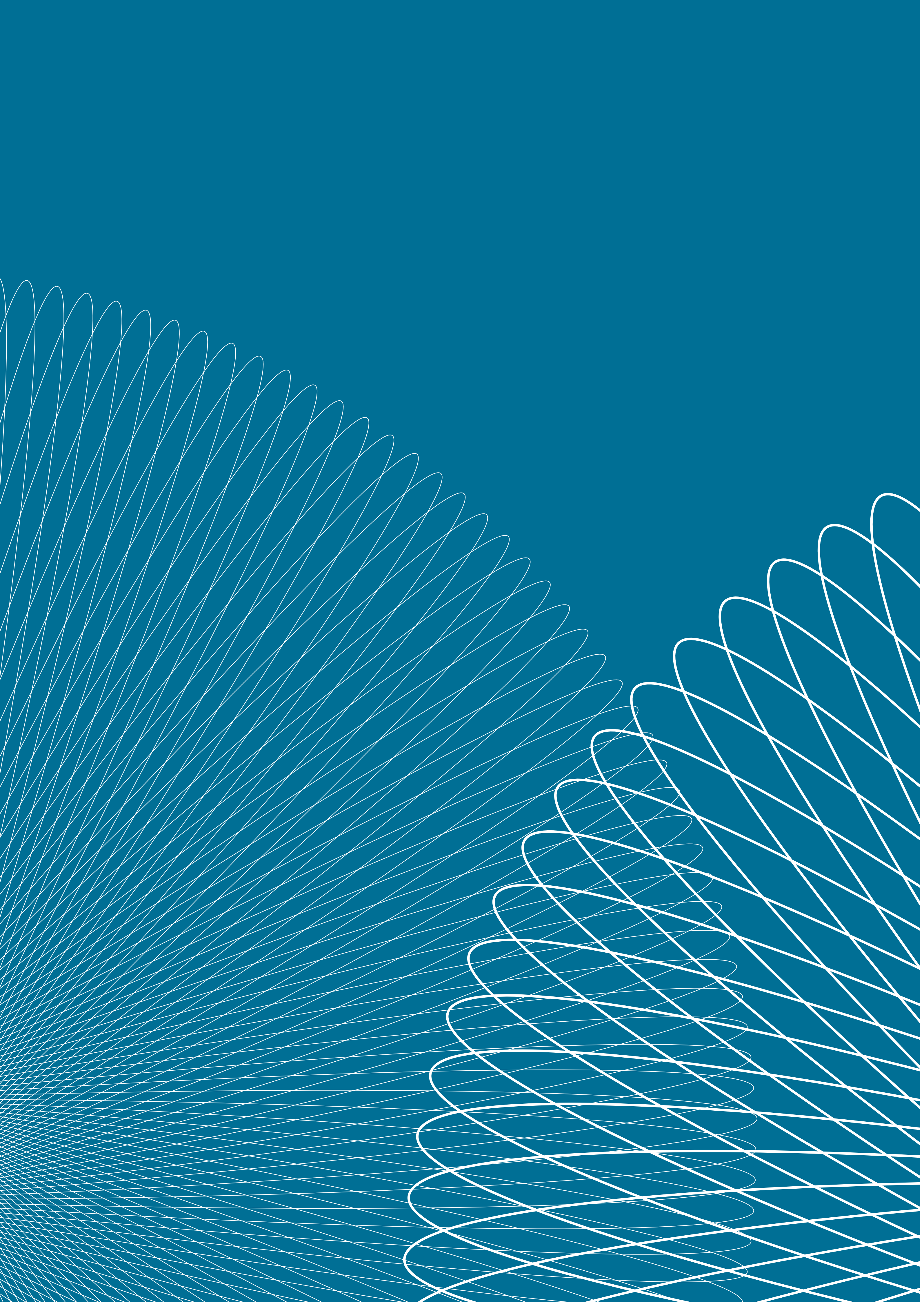
CENTRE FOR AUTISM
MIDDLETOWN

Assessment Practice in Autism

Research Bulletin Issue No. 30
December 2019



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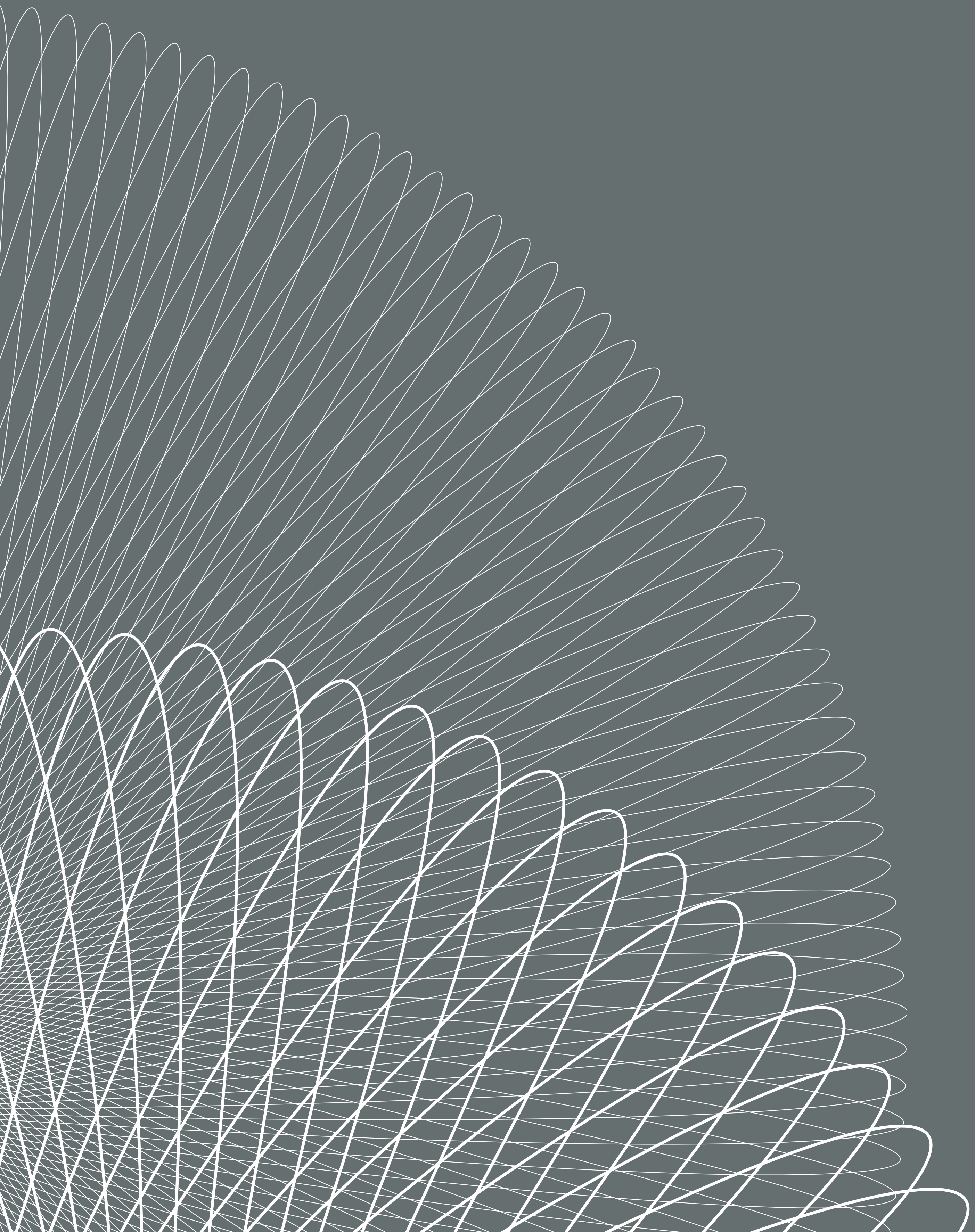


INTRODUCTION

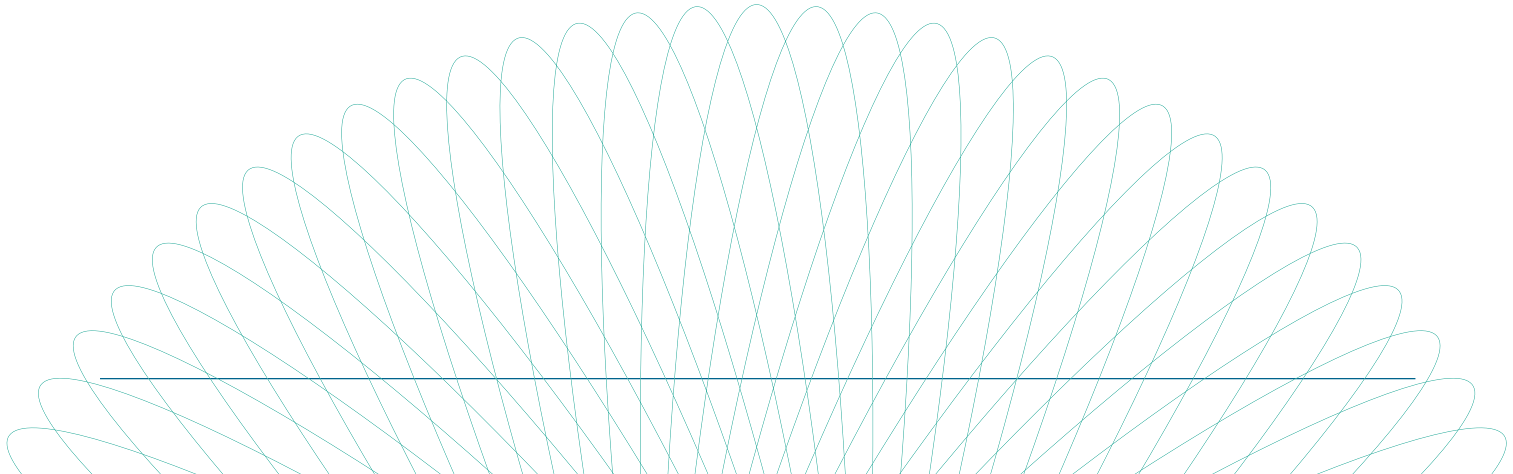
This is the thirtieth Research Bulletin produced by Middletown Centre for Autism and it provides summaries of twelve articles spanning the years 2015 to 2019.

The Bulletin commences with an interview from Professor Tommy MacKay, one of the UK's leading psychologists who works across the fields of educational and child psychology, health psychology, clinical neuropsychology, psychotherapy, teaching and research.

Professor MacKay's principal clinical specialism is autism. He is director of Psychology Consultancy Services, co-founder of the National Centre for Autism Studies at the University of Strathclyde, clinical director of the National Diagnosis and Assessment Service for Autistic Spectrum Disorders, a past president of the British Psychological Society, an academician of the Academy of Social Sciences and a chartered scientist.

He has around two hundred and fifty publications in psychology and has jointly authored books including *Doing Research with Children* and *The Homunculi Approach to Social and Emotional Wellbeing* for young people on the autism spectrum or with emotional and behavioural challenges.

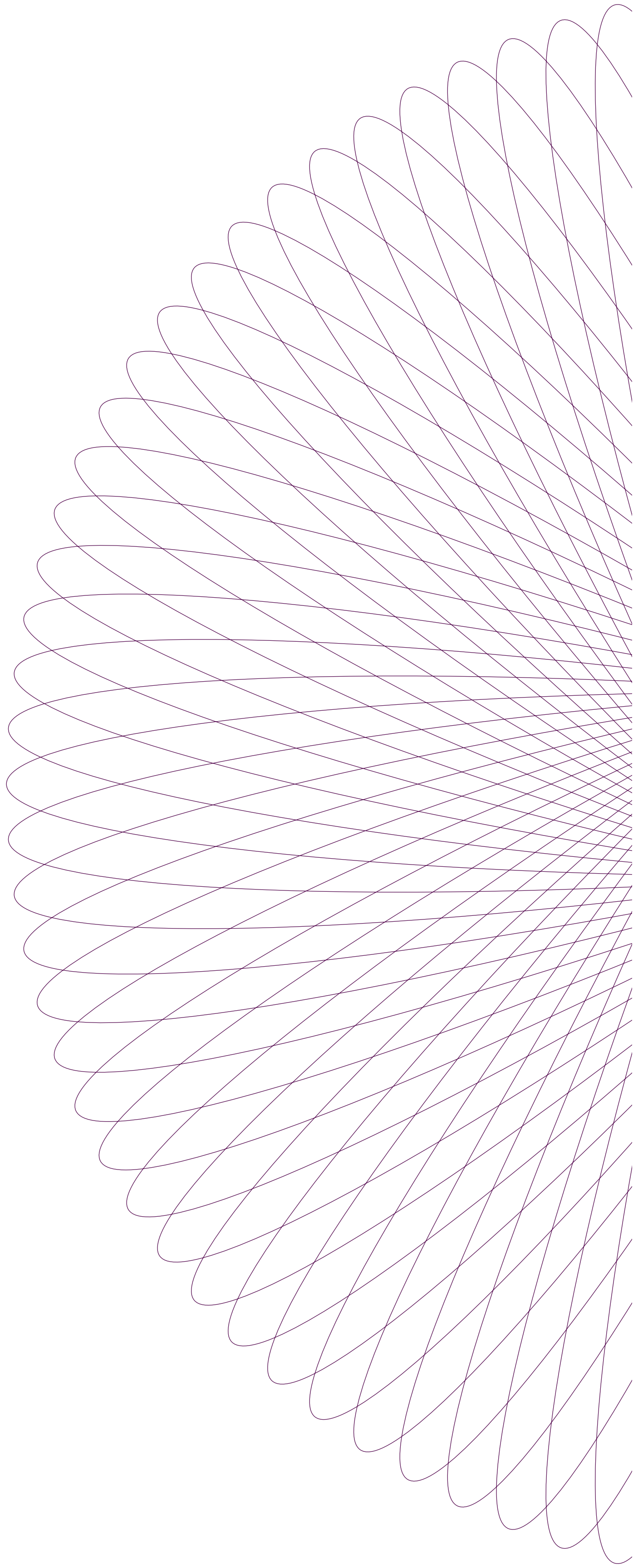
Professor Tommy MacKay has won many honours and awards including Fellowship of the British Psychological Society for 'an outstanding and original contribution to psychology'; the Award for Challenging Inequality of Opportunity; an Honorary Doctorate from the University of Glasgow for his 'significant contribution to educational psychology in Scotland'; an award from the Chartered Institute of Transport for his work on psychology and passenger transport policy; the George and Thomas Hutcheson Award presented to 'inspirational figures' in March 2008; the Award for Distinguished Contributions to Professional Psychology, presented in Dublin in April 2008; the inaugural Public Engagement Award for bringing psychology to a wider audience, presented in May 2011; the Lauriston Broadsword for services to the Baronage of Scotland in July 2013; and election to Fellowship of the British Association of Behavioural and Cognitive Psychotherapies in 2014, a mark of distinction awarded annually for a significant contribution to the advancement of this field. Most recently, he was invited by the British Psychological Society to be the 2018 Vernon Wall lecturer at Oxford last September, and his resulting monograph *Can the psychology of education enhance social wellbeing? A national vision for intergenerational change* was published in November 2019.



His research on raising educational achievement, the subject of his second doctorate, won a Business Excellence Award for innovation and new applications and is the subject of a publication by the Centre for Policy Studies: *A World First for West Dunbartonshire: The Elimination of Reading Failure*. In London, 2007, it won for West Dunbartonshire Council the prestigious MJ Award for 'Best Achievement in Children's Services'. His work contributed to the setting up of Scotland's National Literacy Commission, of which he was a member. Its report, which was endorsed by all political parties in Scotland in December 2009, set out a vision to make Scotland the first nation in the world to eradicate illiteracy.

In February 2010 he was entered in the Gallery of Heroes. His achievements are the subject of a chapter in *Britain's Everyday Heroes* by former Prime Minister Gordon Brown, who described him as 'a visionary and an inspiration', as having a lifelong alignment with the poor and the disadvantaged and as being driven by 'an absolute refusal to accept that anything was impossible'.

Please note that the views represented in this document do not necessarily reflect the views of Middletown Centre for Autism. Reviewers have, where possible, used the original language of the article, which may differ from UK and Ireland usage and the usage of a range of terminologies for autism.



AN INTERVIEW WITH PROFESSOR TOMMY MACKAY

1. Why is assessment critical for supporting the learning needs of children and young people with autism?

Assessment is crucial for supporting the learning needs of all children and young people, and that includes those with autism. I usually divide assessment into four overlapping types according to its purpose. First, there is formulatory assessment, which is used to determine a child's overall profile or position. Second, there is monitoring assessment, used for establishing and checking on progress over time. Third, there is curricular assessment for informing teaching and intervention programmes. Fourth, there is evaluative assessment, used for evaluating research hypotheses.

All of these are important in autism. From the start, accurate formulation is required in terms of clear diagnosis so that the child's overall profile and needs can be properly understood. It is also necessary to have a clear view of a child's cognitive and developmental level and an accurate measure of current attainments and learning level. Regular monitoring is needed to ensure that appropriate progress is being made, together with assessment relating to the curriculum to indicate exactly what steps to take next. Not everyone will be involved in evaluative assessment, but it too is crucial in assessing the merits of different approaches and strategies so that children can have the most effective interventions.

2. What should be the primary goals when conducting an educational assessment with children and young people with autism?

I work a lot with the courts in relation to children and young people with autism. Whatever type of case arises there is one golden rule to guide expert opinion and court decisions: the best interests of the child are paramount. That should be the overriding consideration in educational assessment. In schools, teachers have to follow a variety of assessment expectations, varying from national requirements at particular stages to routine ongoing classroom tests; however, the question always has to be asked about how the assessment will support the child's interests. For the teacher or other educational professional, the assessment will normally be valuable to the extent that it signposts the way forward by identifying the child's current needs and achievements and pointing to the next step to be taken.

3. Can the assessment process be challenging? What accommodations can be made to ease potential difficulties?

Assessments can be challenging for any child, but there are particular challenges for those with autism. At the core of our postgraduate autism lectures is my lecture on psychological theories of autism, which looks at the nature of autistic difficulties and the mechanisms underlying these. This highlights areas that point to where some of the key challenges are likely to lie.

First, there is executive function, usually compromised in autism. This includes difficulties in organisation, monitoring, planning and attention shifting, together with weaknesses in working memory and processing speed. All of these factors are normally involved in how assessments are tackled and how all parts of them are completed in time. Then there is central coherence, the ability to move from detail to the bigger picture, from text to context, a crucial factor in comprehension. In addition, there is theory of mind, the ability to understand the thoughts and intentions of another party. For many children with autism they will not read the situation intuitively in the way other children will and understand why someone else is wanting them to work at their fastest, to do their best or to answer questions whether they find them interesting or not.

In addition, as many of the children will have a range of sensory issues, there may often be aspects of the assessment environment that present a challenge but which may not be very obvious. Many children also have a built-in demand avoidance, so getting them to perform in an assessment and to follow instructions may prove futile.

Awareness of these factors can point to some of the accommodations that will help. This can include breaking the assessment down into parts and doing them one part at a time.

4. How inclusive are assessments when considering the diverse needs of children and young people with autism?

There is often a considerable mismatch between standard forms of assessment and the needs of young people with autism. Giving a child an assessment is based on certain assumptions that we take for granted. We assume, for example, that a child is expected to be motivated and attentive. Typical children want to do their best, to please the examiner, to do better than other children. The approach is based on some variation of the format all psychologists are familiar with – 'Put these pieces together as quickly as you can'. Whatever the task, the assumption is that the child has the motivation and social understanding to respond. Meanwhile the child with autism maybe be sitting thinking 'Why?', especially if one piece is much more interesting than another piece.

5. In considering the concept of inclusive assessment, to what degree should modifications to a standard form of assessment provide adequate assessment of those with autism?

I often find that people who are not autism specialists shy away from engagement with children and young people on the spectrum because they feel they lack skills and it is something to pass over to the experts. Certainly, autism-specific knowledge and experience are very important and often essential; however, I usually reply by telling people first of all that the child with autism is a child, and to put that first. Secondly, they are a child with additional needs, so that must be considered. Thirdly, they have autism. By responding in this way they find so much that benefits the child with autism because it benefits all children. Similarly, there are many children and young people on the spectrum who will cope well with standard forms of assessment, and that is a good starting point.

To the extent that we find ordinary approaches not suitable, we move increasingly towards special methods. Sometimes the child will just need some help, encouragement, explanation or orientation; however, when a standard form of assessment is not meeting a child's needs it is best just to abandon it, to come back to asking what actually needs to be assessed to serve the child's best interests and to using any alternative approach that is workable.

6. Do you think it is important to consider alternative forms of assessments for pupils with autism? What form can this take?

At our National Diagnosis and Assessment Service for ASD we are often assessing young children who are simply not engaging and who may also be hyperactive. We are unable to use normal assessment methods – but we still have to assess as best we can. We are therefore using, devising and improvising strategies accordingly, often utilising observation of what a child is actually doing and gathering systematic information on relevant performance from parents or other key workers.

Sometimes there are equivalent standard assessments that suit autism better. A good example is in the field of cognitive assessment. The main intelligence tests are often quite unsuitable, being too long and too loaded with items that discriminate against autism difficulties, like social comprehension. The work of Michelle Dawson and her colleagues demonstrated that simpler, shorter and more concrete standardised assessments such as Raven's Matrices could do the job much better. The more direct and concrete a test is the more it is likely to serve its purpose. Many standard educational tests are designed to be more interesting by building in items based on normal social or empathetic understanding, but they can be replaced by simple tests assessing the same things in a more concrete way.

Standard assessments will always be important, but educational psychology has moved away a lot from standardised tests to dynamic assessment, where the assessor interacts with a child at their own level and assesses how they respond and learn in the context of teaching and practice.

7. From your experience, how regularly should a child be assessed?

There is an old saying that 'you don't fatten a pig by constantly weighing it'. I have seen many assessments which seem to have more to do with servicing the needs of the assessors for regular assessments than the needs of children; however, while many formulatory assessments serve to establish a profile that may not really require to be revisited once it is done, it is a different matter with monitoring and curricular assessments. With these I am a great believer in frequent and indeed ongoing assessment.

For our major research on the West Dunbartonshire Literacy Initiative, through which we eradicated illiteracy throughout an entire education authority for all children and not just for those with autism, I designed very simple assessments for early literacy. These were carried out annually for every child, but for our special interventions we were reassessing every school term. At classroom and individual-child level we focused on assessment as being a constant process. The child's position on a new skill being taught would be assessed in a simple, practical way, the teaching would take place and the child would be assessed on that skill again. It was an ongoing, reiterative – and highly beneficial – process.

8. What advice can you give regarding implementation of assessment findings into practical strategies?

My advice here is very simple: get the assessment right – and the implementation will follow naturally. We designed our own educational assessment materials using the seven measurement principles set out by Bloom and Fischer – reliability, validity, utility, directness, reactivity, sensitivity and feasibility. That was not for the most part a complex, technical process but a very straightforward approach. It answered simple questions such as: does the test have face validity in measuring what you actually want to measure? Does it have utility in giving you the information you need to plan your next teaching step? Is it direct in measuring the thing itself and not some psychological construct associated with it? Is it sensitive to change so that it measures small steps and you can see if progress is being made? And is it feasible in terms of the resources you have to carry it out and work with it?

If you adopt these principles for educational assessment, you will find that the assessment is an essential tool in pointing straight to the next steps in implementation.

A MULTI-METHOD ASSESSMENT OF STUDY STRATEGIES IN HIGHER EDUCATION STUDENTS WITH AN AUTISM SPECTRUM DISORDER

BACKGROUND

The number of students with autism attending higher education (HE) is growing; however, when compared to typically developing peers their chances of graduating are lower. This study compares the study skills of HE students with autism to their typically developing peers..

RESEARCH AIM

This study used a multi-method design to investigate whether HE students with autism have more challenges selecting pertinent information from their study materials, have weaker metacognitive abilities and have poorer academic planning and purposeful acting skills than their typically developing peers.

RESEARCH METHOD

A self-report inventory that focused on learning attitude and study strategies was completed by 79 HE students, 26 of whom had a diagnosis of autism and 53 were typically developing peers whose field of study largely matched. The inventory had 10 scales which provided a profile of the students’ three areas of metacognitive knowledge:

- Self-determination
- Self-regulation
- Processing strategies

Think-aloud protocols (TAPs) were also completed by 24 HE students: 12 had a diagnosis of autism and 12 were typically developing peers. Students were asked to express their thoughts, experiences and actions while completing four study assignments. A scoring list was used containing descriptions of study strategies in the areas of:

- Reduction of study material
- Memory support
- Repetition/memorising
- Relevance and context
- Monitoring/processing control

RESEARCH FINDINGS

Students with autism demonstrated greater difficulty than typically developing peers in both the self-report inventory and TAPs in selecting main ideas from the study material and with relevance and context. They used (re)reading more frequently as a strategy to memorise content. The inventory exposed less metacognitive knowledge of study strategies in the group with autism and the TAPs confirmed that they used fewer study strategies during tasks. Students with autism also had a more negative attitude towards their studies, and from a motivational perspective they also found it harder to define the consequences of their vocational choices.

No significant difference was found in either instrument with time management and concentration. Students with autism put as much effort into reducing study material and applied the same memory-supporting strategies, although they did mark and underline significantly less than typically developing peers.

IMPLICATIONS FOR PRACTICE

- HE teachers of students who have autism should provide clear course plans and highlight important deadlines, aims of the course and materials that will be used.
- Teachers should provide best study strategies, synopses, résumés, mind maps and clear instruction on what to pay attention to during class.
- To support students with autism in reflecting on and structuring their work, mock examinations and oral feedback before and after an exam should be provided.
- Exams should be conducted in quiet, distraction-free smaller classrooms.
- As students with autism are distracted by highlighted or underlined course materials, textbooks and materials should be well-structured with a clear layout.

Full Reference

Tops, W., Van Den Bergh, A., Noens, I. and Baeyens, D., (2017). A Multi-Method Assessment of Study Strategies in Higher Education Students with an Autism Spectrum Disorder. *Learning and Individual Differences*. **59**, pp.141–148.

COST OF ASSESSING A CHILD FOR POSSIBLE AUTISM SPECTRUM DISORDER? AN OBSERVATIONAL STUDY OF CURRENT PRACTICE IN CHILD DEVELOPMENT CENTRES IN THE UK

BACKGROUND

The UK's NHS recommends an autism diagnostic process based on guidelines from the National Institute for Health and Clinical Excellence (NICE). Recommendations include the involvement of a multidisciplinary team including a paediatrician, speech therapist and psychologist. These teams may be based in Child Development Centres (CDC) or within Child and Adolescent Mental Health Services (CAMHS). NICE also recommends that alternative explanations for the child's difficulties are considered and that other disciplines, such as occupational therapy, are involved in the assessment. Although NICE recommends the use of tools such as the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Scale (ADOS), the guidelines suggest that no single assessment tool alone is sufficient for an autism assessment.

The presentation of autism varies significantly across individuals. Therefore, the diagnostic process is not straightforward. This, combined with the increased demand for diagnostic assessment, means that autism diagnostic services are stretched. There are currently no national benchmarks for the cost of an autism assessment.

RESEARCH AIMS

The authors aimed to examine the cost to the NHS of a multidisciplinary assessment for autism. They aimed to establish this by investigating the average amount of professional time involved in a typical pathway at a secondary care CDC. They also wished to examine the average amount of children seen in each centre, how happy teams felt with the diagnostic pathway and their perception of the likelihood of receiving an autism diagnosis.

RESEARCH METHODS

An online questionnaire was sent to 20 CDCs in the UK. Questionnaires were completed by 12 out of these 20 centres. The questionnaire asked respondents to report the amount of time members of a multidisciplinary team typically took to complete an assessment for autism. Respondents were able to describe the typical stages of assessment and their satisfaction with the assessment pathway.

The cost of assessment was calculated by multiplying the hourly pay of the staff involved by the amount of time staff members worked on the average assessment.

Data was collected between January and May 2013.

RESEARCH FINDINGS

Of those centres who returned their questionnaires, one centre assessed only preschool children, two centres assessed 0–11 year olds, six centres assessed 0–16 year olds and three centres assessed 0–19 year olds. Ten out of the twelve centres conducted initial screening assessments before undertaking a full assessment. A median of 140 children received an assessment in each centre per year, with a median of 60 children who enter the diagnostic process receiving a diagnosis of autism.

For a full assessment, the median time taken was thirteen hours. This figure excludes data from one of the centres who was unable to reflect their pathway on the questionnaire. Between three and seven staff members were involved in the assessment. This most often included a paediatrician, clinical psychologist and speech therapist.

The cost of a full assessment was between £650 and £1000, with a median cost of £809. The cost was not directly related to the number of professionals involved, but cost was directly related to the length of time taken in the assessment. The number of hours that doctors were involved was also closely related to cost.

Nine of the respondents suggested that the resources available decided the diagnostic pathway. Respondents suggested that there was a need to increase the capacity of their service. Two of the respondents suggested that they were satisfied with their current diagnostic pathway. One respondent suggested that they had difficulties with meeting NICE guidelines and another suggested that an increase in the number of referrals had resulted in shorter assessments.

Three of the CDCs reported that they provided follow-up care for families. One centre noted that it provides short-term care but is experiencing pressure to stop longer follow-up provision.

IMPLICATIONS FOR PRACTICE

(by the authors)

- The autism diagnostic process takes around thirteen hours per child, with a median cost of £809. This finding will be important to inform the future funding of autism diagnostic services.
- A high amount of involvement from doctors in the diagnostic process increases costs. This suggests that it is good practice and cost saving to involve Allied Health Professionals in the diagnostic process for elements of the assessments that do not require a doctor's skills.
- Respondents noted that the diagnostic process was resource dependent. The authors suggest that diagnostic services could be improved if funding recognised the realistic assessment costs, allowing services to receive the appropriate level of resources rather than having to make do with what is affordable.
- The additional funding needed to cover the cost of adequate diagnostic assessment should be offset by longer-term savings in money needed to support individuals with autism and their families. Employing effective early interventions, for example, can save money across an individual's lifetime.

Full Reference

Galliver, M., Gowling, E., Farr, W., Gain, A. and Male, I. (2017). Cost of assessing a child for possible autism spectrum disorder? An observational study of current practice in child development centres in the UK. *BMJ Paediatrics Open.* 1(1). http://dx.doi.org/10.1136/bmjpo-2017-000052.

NATIONAL STUDY OF SCHOOL PSYCHOLOGISTS' USE OF EVIDENCE-BASED ASSESSMENT IN AUTISM SPECTRUM DISORDER

BACKGROUND

Despite autism being among the fastest growing developmental disability diagnoses, estimates suggest many students remain unidentified. There is therefore a need for special educational teams to have expertise in the identification of autism. This study was based in the USA and explored school psychologists' knowledge of, training and experience with autism on assessment practicalities including areas of training needs.

RESEARCH AIMS

This study aimed to improve understanding on the variables predicting the use of evidence-based assessment (EBA) practices for autism among school psychologists. Impact of demographic characteristics, autism knowledge as well as training and experiences in the use of evidence-based assessments (EBA) were explored.

RESEARCH METHODS

A total of 402 participants were categorised into two groups: those who reported using EBA and those who did not. Participants were recruited from the National Association of School sychologists (NASP) and state-affiliated school psychology organisations. School psychologists experienced in autism developed the autism survey, which was composed of fourteen demographic questions followed by five topic areas:

1. Services provided to students with autism
2. Autism experience and training
3. Autism knowledge
4. Autism training needs
5. Autism eligibility and diagnosis

Paper surveys were mailed to a randomly selected sample of NASP members. The electronic survey was delivered to state-affiliated school psychology organisations using Survey Monkey software.

To understand predictors of the use of EBA, a number of analyses were completed:

- Bivariate correlations: to identify significant relations between use of EBA and responses to items from the autism knowledge and autism experience and training scales
- Chi-square tests: to examine relations between use of EBA and six demographic variables
- Chi-square test of independence: to examine administration practices of autism-specific measures and intelligence assessment batteries
- T-test analysis: used to establish differences in reported training needs and use of EBA practices.

RESEARCH FINDINGS

COf the 402 psychologists surveyed less than 25% engaged in EBA as defined by this study. Within the school psychologists who were implementing EBA, the majority relied on autism checklists that provide limited information. The EBA group were more likely to include a standardised measure of intelligence than the non-EBA group. Three significant variables were identified on predictors of EBA use:

1. Experience with children aged 3–5 years. This may be due to autism concerns being identified in early childhood and comprehensive autism assessments often taking place at this point
2. Geographical location with the percentage of psychologists who engaged in EBA being greater in southern and western regions of the USA.
3. Experience and training in autism. This was the strongest predictor of EBA practices.

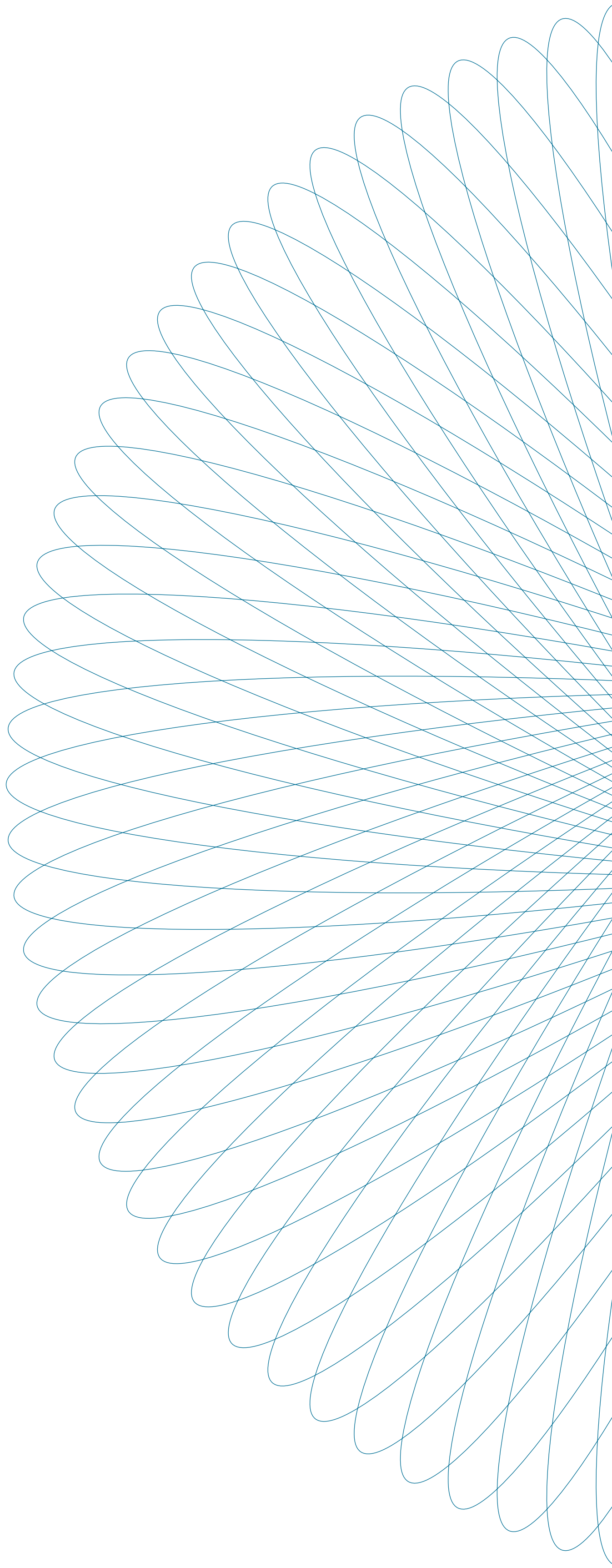
It was unexpected that knowledge of autism was not a significant predictor; therefore, possessing a high level of knowledge of autism did not differentiate psychologists who used EBA from those who did not.

IMPLICATIONS FOR PRACTICE

- Employers of school psychologists may wish to provide opportunities for autism-specific training to increase skills and mandate several hours of professional development in this area.
- Employers may consider a rotation scheme for psychologists within local school-district autism teams.
- Extensive training for a small group of school psychologists to specialise in an autism diagnostic or identification team may also be considered by employers.

Full Reference

Aiello, R., Ruble, L. and Esler, A.N., (2017). National Study of School Psychologists' Use of Evidence-Based Assessment in Autism Spectrum Disorder. *Journal of Applied School Psychology*, **33** (1), pp.67–88.



PARENTS SUGGEST WHICH INDICATORS OF PROGRESS AND OUTCOMES SHOULD BE MEASURED IN YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDER

BACKGROUND

Despite recognising the importance of early identification and diagnosis for best management of autism spectrum disorders (ASD) and the growth in interventions with improvements in trial quality, there is a persistent lack of agreement on the most important outcomes to target and measure in evaluative research. This stems from evaluation interventions of children with autism often being hindered by the multitude of outcomes, measures and tools used that are rarely selected with any theoretical reasoning and have poor variable or inadequate evidence of vigorous measurement properties. The research described in this paper was part of a process of evidence synthesis commissioned by the UK National Institute for Health Research (NIHR), namely The MeASURe Project (Measurement in Autism Spectrum disorder Under Review).

This paper reports on a scoping review of qualitative studies and consultations with parent advisory groups from the MeASURe Project.

RESEARCH AIMS

In consultation with parents the primary aim of this paper was to explore and identify what outcomes parents viewed as important for measuring the progress of their young child (up to the age of 6 years) with autism. While conducting this part of the research, the similarities and differences among parents, professionals and researchers on the importance of outcomes were explored.

RESEARCH METHODS

Two research methods were employed.

Scoping review

A scoping review of qualitative studies of what matters to parents was conducted. A systematic approach was undertaken using a range of databases to extract research papers published in English to the end of 2012. Two blocks of search terms were tailored to each database with block one terms allocated for autism and block two for qualitative study designs. Papers were selected if they acknowledged themes which concerned parents' hopes for their children, experience of assessment of their children and their priorities for intervention and education of their children, therefore taking a broad approach to potential identification of 'outcomes'. Exclusion criteria included: ASD not being a core focus; the paper did not include parental responses; parents views and future hopes were on adult children with autism and not young children with autism; the focus was on process, i.e. the challenges papers encounter in assessing services; and papers were not in English.

Initial Consultation with Parent Groups

To explore with parents what outcomes they saw as important for measuring the progress of their young child with ASD over time.

Parent advisory groups were recruited in the north-east, south-east and south-west of England. Research ethics were not required as the study was perceived as public involvement. Three groups were sent emailed invitations as briefly described below:

- One group was derived from families of disabled children who volunteer as partners in research through a Family Faculty. Parents of children with autism from the Family Faculty were emailed with an invitation: twelve expressed interest and seven participated in one or more meetings.
- At another site a clinical team involved in providing advice on an ad hoc basis to families of young children with autism emailed ten parents: six participated in one or more meetings.
- At a third site parents of children with autism aged ten years or under who had been in contact with the voluntary organisation were also invited via email: four participated in one or more meetings.

A total of seventeen parents of children with autism (with a range of abilities) were involved in discussion meetings. Parents were incentivised to participate and travel via a shopping voucher. At each site the discussion was led by two facilitators, i.e. a member of the project team and a parent involvement coordinator. Discussions were summarised and organised into themes by the parent involvement coordinators.

Consultation with Parents About Outcome Constructs

To explore how parents would prioritise a broad range of outcomes

Stage one of the MeASURe systematic review involved the identification of outcome constructs and measures used in early intervention and longitudinal studies. A set of sixty-two outcomes were constructed from the systematic review together with themes from the scoping review of qualitative research and the findings from consultations with parents.

Two independent members of the project team, who were not autism specialists, created 'lay wording' versions of the compiled constructs. These were then checked for fidelity of meaning by an autism content expert. At stage two of parent group meetings, a Q-sort method was used to allow parents to rate the relative importance of the sixty-two outcomes. This allowed for the identification of the priority preferences of parents and for observation of the processes and discussions that parents had while working together on this task. Following this exercise, the sixty-two constructs were presented on typed cards, in a random order, to each of the three parent groups. Parents were then asked to discuss each construct in terms of its importance. Importance was defined as 'the importance of various things which could be measured when tracking the progress of children with autism aged up to six years or in measuring the outcome of specific preschool intervention'. Cards were sorted onto a pyramid-shaped grid and labelled for levels of importance across an eleven-point scale, with no construct being considered as unimportant. Ratings from each group were averaged.

Discussion with Parents, Professionals and Researchers

To explore similarities and differences in how various stakeholders considered the importance of outcomes to be measured.

A discussion day was held comprising three parents of children with autism, one young adult with autism, who was only a social researcher, eight professionals working across health or education and four researchers who work with children with autism. Four small groups were formed of individuals with similar backgrounds who also used a Q-sort method to rate by importance a reduced set of constructs that included ten that were rated the most important by parent groups as well as ten constructs measured important by professionals as reported within a survey. At the end of the discussion day the entire group of participants discussed the similar and different views.

RESEARCH FINDINGS

Review of Qualitative Literature

The initial search identified 152 papers of which seven papers met inclusion criteria, that indicated that the quality of data was varied and broad in focus/topic. Three papers reported data relevant to parent outcomes while three papers reported data relevant to child outcomes. One paper reported both child and parent outcomes while another paper reported data directly gathered from children and young people with autism. The age of children reported across the papers represented those aged up to twenty-one years with the diagnosis of children relying on parental reports.

Initial Consultation with Parent Groups

During the consultation stage, parents considered outcomes that were typically assessed or not assessed by professionals. Parents expected professionals to concentrate on assessment of the core autism features; however, they suggested that the child's skills, as well as their needs/difficulties should be recognised. Parents noted happiness, problematic habit behaviours (such as sleep, diet- and food-related behaviours, sensory processing issues and toileting), behaviours that challenge and meltdowns (self-harm, hitting out, anxiety, stress). The importance of measuring social communication and social functioning (playing with others, playing alone, interacting, understanding and communicating) for young children was welcomed by parents. Parents further recommended that future building blocks of learning, independence and life skills were important. It was also recognised that although some activities and skills may not seem important or relevant for young children, they were significantly important for their future development (e.g. making and keeping friends).

Parents further recommended that as part of the assessment process, the use of video recording of children's behaviour across their usual environments and not just in clinics should be considered.

Consultation with Parents about the Outcome Constructs

The constructs rated on average as 'more important' were:

- Body functions/impairment: hypersensitivity, happiness, anxiety and unusual fears, distress, nonverbal ability, expressive and receptive language.
- Activity-level indicators: aggression, sleep problems, school readiness.
- Participation: self-esteem, relationships and siblings, being bullied/rejected, no awareness of danger.
- Family: parental stress.

Across all groups, the highest level of consistency in rating constructs were aggression and sleep problems. Parents felt that it was important to measure outcomes such as happiness for all children as well as anxiety and distress as these aspects impacted on the quality of life for the child and the family unit. Parents also felt that they had not fully understood what autism was at the start of assessments and lacked knowledge on how, for example, joint attention skills impacted their child's language development.

Discussion with Parents, Professionals and Researchers

The discussion group highlighted differences across the groups. Parents and young adults with autism were of the strong opinion that it is important to place emphasis on what children can do, to view autism as a 'difference' rather than always using a 'deficit' model and that supports should be in place within their environment to enable children to progress. Parents appreciated that clinicians had mentioned the importance of assessing the skills of care and education staff. Clinicians had reflected how their approach to assessment and intervention was formed on the basis of the 'medical' model: early identification of specific difficulties, choice of treatment and prevention of secondary 'impairments', etc.

Parents valued a wide range of outcomes across all domains of their child's functioning, abilities, difficulties, everyday activity and participation.

IMPLICATIONS FOR PRACTICE

(by the authors)

This paper has highlighted several implications for future practice:

- The importance of engaging with parents and adults with autism in research processes when a study is in its infancy, working with researchers to agree research questions, understanding the research design and working together to identify the most appropriate outcomes to measure.
- The need to address outcome measures for older children and adults with autism and future consultation across a range of ages and abilities.
- Additional work is further required to provide evidence for setting reasonable time frames within which a generalisation of skills might be expected to be observed in children with autism. For example, gaining new skills such as joint attention might be observed across a 3–4 month period but generalisation across environments may take longer.
- Future initiatives should focus on developing valid and reliable tools that measure outcomes that are considerate of what is important to those with autism and their families.

Full Reference

McConachie, H., Livingstone, N., Morris, C., Beresford, B., Le Couteur, A., Gringras, P., Garland, D., Jones, G., Macdonald, G., Williams, K. and Parr, J.R., (2018). Parents Suggest which Indicators of Progress and Outcomes should be Measured in Young Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders.* **48**(4), pp.1041–1051.

MEASURING REPETITIVE BEHAVIORS AS A TREATMENT ENDPOINT IN YOUTH WITH AUTISM SPECTRUM DISORDER

BACKGROUND

Restrictive interests and repetitive behaviours are a key diagnostic feature of autism spectrum disorder, comprising one half of the dyad of impairment. Restrictive interests and repetitive behaviours vary greatly from individual to individual but for some they can interfere with other more purposeful activities and can be stigmatising. Where restrictive interests and repetitive behaviours are impacting on daily routines and general functioning they can be supported through intervention. However, there is a lack of suitable and reliable assessments for restrictive interests and repetitive behaviours, limiting the ability to determine efficacy of treatment post-intervention. This study therefore involved a review of assessments in this area and their appropriateness for clinical trial outcome measurement.

RESEARCH AIMS

This study aimed to review available assessment tools for measuring restrictive interests and repetitive behaviours. It sought to build upon previous reviews of assessment tools by focusing specifically on the readiness of the tools for outcome measurement in clinical trials.

RESEARCH METHODS

Following review of relevant literature twenty-four assessment tools were identified for further analyse that was undertaken by a panel of experts. Experts had clinical trial expertise in autism or restrictive interests and repetitive behaviours or were Autism Speaks science programme staff. During the review the panel had two meetings and monthly conference calls over a fourteen-month period. The twenty-four selected tools were first categorised into type (questionnaire, observation or interview); respondent method (parent, self or therapist completed); what the tool sought to measure; time to administer; and demographic target, for example age or cognitive level. The assessment tools were evaluated in terms of content and construct validity, consistency and reliability, particularly in terms of clinical relevance. Measures were classified as appropriate, appropriate with conditions, potentially appropriate, unproven or not appropriate.

RESEARCH FINDINGS

Of the twenty-four assessment tools that were selected at the outset of the study five were considered appropriate with conditions in terms of their suitability for clinical trial outcome measurement. These were:

1. Children's Yale-Brown Obsessive-Compulsive Scales for Pervasive Developmental Disorder
2. Repetitive Behavior Scale-Revised
3. Aberrant Behavior Checklist Stereotypic Behavior Subscale
4. Stereotyped Behavior Scale
5. Repetitive Behavior Questionnaire

Overview and discussion of each of the measurement tools is contained within the study report.

IMPLICATIONS FOR PRACTICE

- The study provides a detailed review of suitable assessment tools for restrictive interests and repetitive behaviours that can be used as outcome measurement in clinical trials.
- The authors reported that other measurement tools reviewed may be useful for different purposes such as categorising or screening.

Full Reference

Scahill L,. Aman, M.G., Lecavalier, L., Halladay, A.K., Bishop, S.L., Bodfish, J.W., Grondhuis, S,. Jones, N., Horrigan, J,P., Cook, E.H,. Handen, B.L., King, B.H., Pearson, D.A., McCracken, J.T., Sullivan, K.A. and Dawson, G., (2015). Measuring Repetitive Behaviors as a Treatment Endpoint in Youth with Autism Spectrum Disorder. *Autism*. **19**(1), pp. 38–52.

THE SEARCH FOR AN EARLY INTERVENTION OUTCOME MEASUREMENT TOOL IN AUTISM

BACKGROUND

There is increasing evidence that early intervention can effectively improve skills and abilities of children with autism, but there is an ongoing search for an agreed gold standard tool for measuring progress and outcome. To effectively measure the outcomes of an early intervention the measurement tool needs to be reliable, valid and sensitive to change in the core domains of autism.

RESEARCH AIM

The aim of this research study is to further investigate the efficacy of the Social Orienting Continuum and Response Scale (SOC-RS), which is a directly observable measure of social interaction skills in young children with autism. Previous research has determined that this tool encompasses the core features of autism within social communication and has been specifically developed for use with children with autism. This study will focus on whether the tool is sensitive to change over a short period of time (seven months instead of two years). It will also investigate whether it measures treatment effect when comparing groups who have and have not shown behavioural change in response to intervention.

RESEARCH METHOD

The children selected for this study had originally participated in a controlled intervention study (fifty-one children) where parents participated in the More Than Words training programme. They were selected based on whether they had exhibited improvements in social communicative behaviours or not over the seven-month period since their parents' involvement in this intervention.

The researchers placed twenty preschool-aged children with a confirmed diagnosis of autism into two groups labelled 'progress' and 'no progress'. The groups were deliberately kept small to maximise differences between them known as 'extreme groups'.

Children received video-recorded assessment visits each time the Autism Diagnostic Observation Schedule (ADOS) was administered. The films were used as the raw data for completing SOC-RS ratings in this research. Both raters were blind to time and group status.

FINDINGS

Effects of Group and Time:

Researchers used Analysis of Variance (ANOVA) on each item score and on the Social Orienting Composite to test whether the SOC-RS is sensitive to change over a short time (seven months) and if it's sensitive to interactions between group and time. The five items were: referencing, social smiling, orienting to name, joint attention initiation and joint attention responding.

ANOVA results showed main effects of time in referencing only and not for other items. They found moderate effect sizes for joint attention responding and joint attention total items but did not achieve statistical significance. There were no significant interactions between time and group for individual items.

Social Orienting Composite showed moderate effect size, but the interaction of time and group did not show significance. The researchers suggest that a larger sample size may show a greater interaction.

Categorical Differences:

Chi-square testing by the researchers indicates significant between-group differences in joint attention responding at time 2 only and in orientating to name at time 2 only, which indicates the measure detects differential change over time between groups.

IMPLICATIONS FOR PRACTICE
(by the authors)

- The Social Orientating Composite score and the individual item of referencing were sensitive to change over a time period of seven months in comparison to two years in the original study.
- Results indicated the categorical scores that can be extracted from the SOC-RS may be more sensitive to differential change than continuous variables that comprise the overall composite score.
- The measure was not sensitive to group by time interactions and so does not seem suitable as a measure of intervention efficacy. SOC-RS measures five dimensions of social communicative behaviour, therefore a measure that can assess a broader range of skills may be more effective in detecting subtle differences in change over time between groups.
- The SOC-RS has been shown in its development study to be a valid and reliable approach to measuring skill change over time in young children. The time it takes to derive SOC-RS codes from ADOS footage limits its use in clinical practice.

Full Reference

Fletcher-Watson, S. and McConachie, H., (2017). The Search for an Early Intervention Outcome Measurement Tool in Autism. *Focus on Autism and Other Developmental Disabilities.* **32**(1), pp.71–80.

AN INTERNATIONAL REVIEW OF AUTISM KNOWLEDGE ASSESSMENT MEASURES

BACKGROUND

Research has found that in communities where knowledge and awareness of autism is low, the stress and burden experienced by families with children diagnosed with autism increases significantly. Additionally, this lack of knowledge fuels stigmas and misconceptions about autism that further disadvantages families.

Increasing autism knowledge should reduce the stress and inequalities experienced by families; as such, the ability to thoroughly assess autism knowledge is necessary to concentrate efforts in improving autism awareness, which in turn should reduce these disparities.

RESEARCH AIMS

This study reviewed western and international literature to examine measures used to assess autism knowledge and aimed to:

- provide an evaluation of the methodological strengths and weaknesses of this literature, discussing the psychometric considerations of each assessment.
- provide both an overview of existing measures as well as recommendations for making methodological improvements to future measures designed to quantify autism knowledge.

RESEARCH METHODS

A systematic search of databases, such as PsycINFO, Web of Science and Google Scholar, was conducted to identify articles that:

- featured a survey instrument used to assess autism knowledge with quantitative methods.
- were published in a peer-reviewed journal prior to November 2015.

After identifying the sixty-seven relevant articles, the authors extracted data regarding:

- the characteristics of the participants' for whom autism knowledge was assessed.
- the assessment measure used.
- the measure subdomains.
- the most frequent words used in each measure's subdomains using NVivo (version 10 for Windows) qualitative coding software (QSR International Inc, 2015) to look for trends in word frequency regarding (a) symptoms or diagnosis (b) aetiology and (c) treatment and outcomes.

RESEARCH FINDINGS

This review of sixty-seven peer-reviewed articles identified forty-four unique autism knowledge measures across sixty-seven studies conducted in twenty-one countries.

Methodological strengths and weaknesses:

- Measures used in each study were evaluated in terms of psychometric strength. Of the sixty-seven studies reviewed, only 7% were rated as using a measure with strong psychometric support compared to 45% that were rated as using a measure with no reported psychometric support.

Overview of existing measures and recommendations:

- Examining the content overlap and subdomains of autism knowledge assessed, most words (53.3%) addressed the subdomain of symptoms, fewer (15.6%) addressed the subdomain of aetiology and roughly a third (31.1%) addressed the subdomain of treatment.
- Based on these findings the authors noted that although the amount of research investigating autism knowledge has increased in the past five years, efforts are needed to synchronise the research in this area as measures reviewed lacked generalisability and cross-cultural utility.

IMPLICATIONS FOR PRACTICE (by authors and reviewer)

The authors of this study recommend that researchers should work towards:

- creating a new measure of autism knowledge that is cross-culturally valid and psychometrically sound.
- extending current research in this area and cross-culturally adapt assessment measures.

For parents and educational professionals this study highlights the importance of:

- understanding families', schools' and communities' knowledge of autism to effectively build and support capacity of same.
- considering families', schools' and communities' knowledge of autism and working together to select appropriate strategies for both the individual with autism and the supporting adult's level of experience and knowledge of same.
- evaluating the supporting adults' and services' understanding and knowledge of autism and working together to reduce inconsistencies of same.

Full Reference

Harrison, A. J., Slane, M. M., Hoang, L. and Campbell, J. M., (2017). An international review of autism knowledge assessment measures. *Autism*. **21**(3), pp. 262–275.

ASSESSMENT AND TREATMENT OF ANXIETY IN YOUTH WITH AUTISM SPECTRUM DISORDERS

BACKGROUND

Anxiety symptoms are associated with a diagnosis of autism spectrum disorder (ASD), particularly in youth. The research conducted focuses on both assessment and treatment of anxiety primarily in ASD. It is aimed towards assisting primary caregivers of youths with an ASD diagnosis.

RESEARCH AIMS

Research suggests that 39.6% of youths who have an ASD diagnosis also have a minimum of one anxiety disorder. The process of diagnosing and assessing anxiety in youths with ASD is found to be challenging because of the difficulties associated with having ASD.

Proven treatment for anxiety in youths with an ASD diagnosis is limited. Results offer reasonable evidence for the significance of cognitive behavioural therapy (CBT) and an absence of trials investigating pharmacologic treatments specifically for the treatment of anxiety in youths with ASD.

It is stated that there is little training and knowledge for a majority of primary caregivers who are managing youths with ASD and co-occurring psychiatric conditions.

The purpose of the current study is to establish a systematic approach for assessment and treatment of anxiety in youths with ASD and provide treatment recommendations including assisting the clinician in determining when it is beneficial to refer on to a mental health specialist.

RESEARCH METHODS

Anxiety Workgroup comprises a multidisciplinary team of researchers and clinicians including child psychiatrists, developmental paediatricians and a clinical psychologist. The workgroup has extensive clinical experience working with youths with ASD. They are based throughout fourteen ASD centres in the United States and Canada. They developed the current assessment and treatment approach implementing a systematic multiliterate process.

Between April 2014 and November 2014, the workgroup discussed best practice strategies for both assessment and treatment of anxiety in youths with ASD. Reviewing current and relevant studies relating to anxiety and ASD, the workgroup also discussed clinical practice patterns.

For the assessment process the workgroup focused their research on gleaning evidence from manuscripts indexed in PubMed and/or PsycINFO, as well as book chapters published between 2000 and 2014.

Recommendations for treatment were based on results from a systematic review of anxiety treatment studies published between June 2013 and January 2015.

Clinical consensus was attained through an iterative process. All workgroup members were essential and their contributions valued until all members reached a consensus with the final revision.

RESEARCH FINDINGS

Research found that applying a systematic process to assessing anxiety provides clinicians with a standardised approach that is significantly useful in assessing and providing relevant treatment options for anxiety in youths with ASD.

For assessment purposes the workgroup has identified a list of five recommendations. These include:

1. Perform a developmentally appropriate multi-informant and multi-method assessment of anxiety.
2. Assess for specific anxiety disorders and anxiety symptoms related to the core symptoms of ASD.
3. Assess and treat other psychiatric and medical conditions that may cause or aggravate anxiety.
4. Address psychosocial stressors or suboptimal behavioural and educational supports that may be contributing to anxiety.
5. Assess the degree of anxiety-related impairment.

For treatment of anxiety in youths with ASD the workgroup has identified a list of four recommendations. These include:

1. Psychoeducation and coordination of care are the first steps of treatment.
2. Anxiety can be treated with modified CBT techniques.
3. Certain medications can be considered for the treatment of anxiety.
4. Referral to a mental health clinician if anxiety is extremely impairing or is not responding to interventions.

IMPLICATIONS FOR PRACTICE (by the authors)

- The development of a systematic approach is useful for all clinicians working with youths with ASD who are presenting as anxious.
- The systematic approach is time-consuming for clinicians; however, it has been suggested that the assessment can be conducted over multiple appointments or delegated by the clinician to a mental health professional.

Full Reference

Vasa, R.A., Mazurek, M.O., Mahajan, R., Bennett, A.E., Bernal, M.P., Nozzolillo, A.A., Arnold, L.E. and Coury, D.L., (2016). Assessment and Treatment of Anxiety in Youth with Autism Spectrum Disorders. *Pediatrics*. **137**(Supplement 2), pp. S115–S123.

EVIDENCE-BASED ASSESSMENT AND AUTISM SPECTRUM DISORDERS: A SCOPING REVIEW

BACKGROUND

Valid and informative assessments are fundamental to the design of interventions, and thus evidence-based practice for assessment is a critical element in improving outcomes. Assessment of the main characteristics of autism, such as communication and language differences, is a critical element in developing appropriate and effective interventions and supports for each individual.

Assessing language and communication in autism faces a number of challenges:

- Individuals present with different communication needs at different ages,
- Individuals may have very different strengths and needs and diverse adaptive and cognitive profiles,
- There is a lack of normative guidance for pragmatic and social communication development,
- Available assessments are not always specific to autism.

RESEARCH AIMS

This scoping review investigated the existing research on the assessment of communication and/or language in individuals with autism. This research aimed to:

- Synthesise the scope of what has been done in validating language and communication assessment protocols for autism.
- Consider developing best practice clinical recommendations based on findings.

RESEARCH METHODS

A systematic search of databases, such as EBSCO, MEDLINE, CINAHL, ISI and Web of Science was conducted to identify articles that were published in English between 1995 and 2013 and addressed:

- speech and language or social communication assessment for individuals with autism,
- or included methods on assessing theory of mind and social interaction skills,
- or reviewed experimental, qualitative and programmatic/descriptive communication in autism.

The first and second authors each conducted an independent search of relevant scholarly databases using search terms (autism, language, assessment, communication).

The authors identified fifty-four relevant articles for review.

RESEARCH FINDINGS

The age ranges covered in the literature surveyed were from infant to adulthood, but approximately 50% (28/54) included elementary or primary age children.

Of the studies identified:

- Ten were reviews focusing on issues such as dynamic assessment, curriculum-based assessment, best practices for working with families and whether community practitioners are consistent in their assessment protocols.
- Six studies investigated language sample analysis, either of natural or naturalistically elicited language; reporting that narrative assessments garner sufficient data.
- Ten studies investigated using observational assessments, incorporating scripted elicitation protocols, and all reported that they found results supporting use of their protocols to measure language and communication in autism.
- Several studies utilised formal tests of language and communication with individuals with autism with varying success.
- Several studies investigated caregiver report-based assessments. The authors of the review recommend its use, either in conjunction with or instead of formal tests of early language development.

Although the literature reviewed provides some modest support that individuals on the spectrum may be successfully assessed with tests normed on the general population, the authors caution that much remains to be done in establishing reliable and valid protocols for language and communication assessment in autism across the age span and ability continuum.

IMPLICATIONS FOR PRACTICE (by the authors)

The authors of this study suggest that a multipronged strategy for assessing speech, language and communication skills of individuals with autism is needed. Such strategies should incorporate:

- a well-rounded protocol for data collection, including language sample analysis of naturalistically collected data, coupled with a structured observation designed to elicit any unobserved, rarer abilities.
- coupling these informal measures with a formal test and/or a norm-referenced caregiver report instrument.

Full Reference

Santhanam, S.P. and Hewitt, L.E., (2016) Evidence-Based Assessment and Autism Spectrum Disorders: A Scoping Review. *Evidence-Based Communication Assessment and Intervention.* **9**(4), pp. 140–181.

EXPLORING ANXIETY SYMPTOMATOLOGY IN SCHOOL-AGED AUTISTIC CHILDREN USING AN AUTISM-SPECIFIC ASSESSMENT

BACKGROUND

Numerous research studies identify anxiety as one of the most prevalent mental health conditions for children with autism, with as many as 84% of autistic children experiencing this condition. However, correctly identifying anxiety symptoms exhibited by children with autism, or understanding how anxiety is experienced by this population, has been challenging due to the lack of suitable assessment tools available. The Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD) is a recently developed tool designed specifically to assess the anxiety symptoms exhibited by children with autism.

RESEARCH AIMS

The aim of this study was to use an autism-specific assessment tool, the ASC-ASD, to investigate the profile of atypical and typical symptoms of anxiety in children with autism and to look at anxiety symptomatology in relation to adaptive behaviour and characteristics of autism. Furthermore, it sought to determine the level of consensus between parent-reported diagnosis of anxiety and ASC-ASD scores.

RESEARCH METHODS

As part of the longitudinal study of Australian students with autism, one hundred parents of children with autism aged between nine and twelve years old participated in the study. Each participating child had a parent-reported diagnosis of autism that was confirmed through community diagnostic reports and the Social Communication Questionnaire (SCQ). In addition to the SQC, all parents completed the Vineland Adaptive Behavior Scales – Second Edition, and the ASC-ASD.

RESEARCH FINDINGS

The data from this study is in line with previous research studies and corroborates the theory that children with autism present with high rates of anxiety. Using an autism-specific anxiety measure, the ASC-ASD, the findings from this study suggest that the anxiety symptoms assessed within are reasonably representative of diverse cohorts of children with autism.

Of the four subscales measured by the ASC-ASD (uncertainty, performance anxiety, separation anxiety and anxious arousal), the items within the uncertainty subscale were those most frequently identified by parents as occurring 'often' or 'always', which supports previous findings that 'intolerance of uncertainty is associated with anxiety in autistic children'. Conversely, items within the anxious arousal subscale were those least frequently identified by parents as experienced by their child. This may be due to the possible differences in interoceptive abilities (the ability to recognise one's own physiological state) in children with autism, the reported higher levels of alexithymia (the inability to describe or recognise one's own emotions) in this cohort or may be that the physiological symptoms go unnoticed by parents or are not communicated to parents by their children.

Of chief importance in this research study was to ascertain if the ASC-ASD could reliably measure autism-specific anxiety symptomatology and not simply characteristics of autism. The research findings suggest that the ASC-ASD does sufficiently distinguish between the presentation of autism and the presentation of autism with a comorbidity of anxiety. However, it should be noted that the authors acknowledge the innate difficulty in differentiating anxiety symptomatology from core autistic characteristics, in particular atypical anxiety symptoms that are inherently linked with the core characteristics of autism.

IMPLICATIONS FOR PRACTICE (by the authors)

- Given that research to date has focused on the typical symptoms of anxiety, a focus on the atypical symptoms of anxiety is a crucial area for future research considering the significant rates of anxiety among children with autism.
- As the ASC-ASD is a new instrument it will necessitate additional validation against present anxiety measures.
- As this study formed part of a larger longitudinal study, the change in anxiety presentation over time can be explored in future studies.

Full Reference

Den Houting, J., Adams, D., Roberts, J. and Keen, D., (2018). Exploring Anxiety Symptomatology in School-Aged Autistic Children using an Autism-Specific Assessment. *Research in Autism Spectrum Disorders.* **50**, pp. 73–82.

DIFFERENCES IN PROFILES OF EMOTIONAL BEHAVIORAL PROBLEMS ACROSS INSTRUMENTS IN VERBAL VERSUS MINIMALLY VERBAL CHILDREN WITH AUTISM SPECTRUM DISORDERS

BACKGROUND

It has been reported that children with autism who are deemed minimally verbal (MV) or those with spoken language difficulties are underrepresented in research, including the area of emotional and behavioural difficulties (EBD). Thus, as we strive for inclusion in education and society, we need to have a more accurate overview of the experiences, strengths and difficulties demonstrated by all children, but in particular those we see as MV. This study addresses this by comparing difficulties experienced by children with MV, of which recent studies suggest this is 30% of the autism population, children with phrase speech (PS) and children who are verbally fluent (VF).

RESEARCH AIMS

As few studies have assessed if and how EBD vary depending on language ability, this study aims to ascertain through the implementation of two assessment instruments: the Child Behavior Checklist (CBCL) and the Aberrant Behavior Checklist (ABC), if verbal ability and, in contrast, difficulty making feelings known and expressing oneself accurately in children with autism has an impact on their emotional and behaviourally acquired skills.

RESEARCH METHODS

This study focused on 6–18 year olds who had a variety of language skills, recognising that 25% of the autism population will have a nonverbal IQ of <70, encompassing 1,937 children (87% males and thus 13% female) with autism. Of these children, 296 were described as MV, 303 as PS and 1,338 as VF. The researchers used two parent reporting instruments: the Child Behavior Checklist (CBCL), a 118-item scale, and the Aberrant Behavior Checklist (ABC), a 58-item scale, to examine if differences on emotional and behavioural development were apparent depending on verbal ability, competence and confidence.

RESEARCH FINDINGS

Neither of the assessment instruments used gave a full picture of the emotional and behavioural needs of the children with autism across all language abilities. Results showed that when using the CBCL, one may underestimate the emotional and behavioural difficulties of those who are MV, whereas using ABC, this underestimation may be with those who are VF. This may be because of the makeup of the assessments themselves. Some of the items in the CBCL are difficult for parents of MV children to assess, whereas the ABC was designed to be used with those with severe learning difficulties, where the assessment is based on external observable behaviour and which may exclude those who are VF.

On the CBCL assessment, VF children were found to have higher levels of internalising difficulties, particularly anxiety, with 45% falling into the clinical range as opposed to children who are regarded as MV or PS. This difference could be because of cognitive ability too, but the study did not have the capacity to fully examine this point.

From analysis of the ABC, MV children showed higher levels of need on the lethargy subscale and MV and PS children had higher levels of hyperactivity.

The researchers, however, feel that language ability must be considered when assessing emotional and behavioural difficulties in children with autism and feel that this may be done in a larger-scale study where the parameters of interest also include cognitive ability.

IMPLICATIONS FOR PRACTICE (by the authors)

- Children with MV are under-represented in research and therefore it can be difficult for parents and professionals to gain as much knowledge, advice and support as they may need.
- Language difficulties and abilities must be considered when assessing emotional and behavioural difficulties.
- To achieve a clearer understanding of the emotional and behavioural needs of all children with autism, irrespective of their verbal ability, both assessments must be carried out as each instrument highlighted particular needs while not fully portraying others.
- As VF children appear to internalise their difficulties, the need for clearly evaluated observations across a range of activities may be needed to ensure these children's needs are recognised and met and they have a more positive means of expressing such needs. VF children may need a structure whereby they can recognise their difficulties and have positive options from which to choose.
- Anxiety is a key area to be addressed. The anxiety of those who are MV may be easier to see and thus allow the parent or professional to intervene and support, whereas those who are VF are seemingly masking or not outwardly sharing their difficulties and are not asking for help or support. The difficulty may be the same, but it can be difficult to support someone if you are not aware they need support.
- We must not overlook those VF children who do not appear to be having difficulty simply because they have not told us. Instead, we may have to look for subtle changes in the child's behaviour – is he or she acting differently, being quieter, not interacting as often or as strongly? All these aspects may indicate need.

Full Reference

Fok, M. and Ball, V. H. (2019) Differences in Profiles of Emotional Behavioral Problems Across Instruments in Verbal Versus Minimally Verbal Children with Autism Spectrum Disorders, *Autism Research.* **12**(9), pp.1367-1375.

CLINICAL VALIDATION OF THE AUTISM BEHAVIOR INVENTORY: CAREGIVER-RATED ASSESSMENT OF CORE AND ASSOCIATED SYMPTOMS OF AUTISM SPECTRUM DISORDER

BACKGROUND

The authors identified the need for a single scale for measuring clinically relevant changes in core symptoms of autism. They found that this absence limits the development and evaluation of new interventions. To address this they conducted an observational study to evaluate psychometric properties of the Autism Behavior Inventory (ABI) and Autism Behavior Inventory – Short (ABI-S) that were designed to focus on parent observations in natural settings on behaviours that might be targets for change over time.

RESEARCH METHOD

Participants numbering 144 took part in this study that comprised two groups over an 8–10-week period.

Focus groups were used that were made up of males and females aged six years and over (average age fifteen years) with a confirmed diagnosis of autism using the Autism Diagnostic Observation Schedule (ADOS). All participants were verbal, based on parents report, and had achieved a cognitive score of above sixty based on an IQ evaluation using Kaufman Brief Intelligence Test-2. Participants did not have a history of or current significant medical, psychological and/or emotional problem that limited participation with study requirements based on clinical judgment.

The control group comprised forty-one typically developing males and females aged six years and over with a score in the normal range on the Social Communication Questionnaire (SCQ), with no major mental or medical concerns and were not taking psychotropic medication.

All participants were requested to maintain ongoing behavioural and/or pharmacologic treatments during the course of the study and it was expected that some changes would be seen in behaviours over the course of the study. Behaviours were measured at baseline and endpoint, 8–10 weeks.

Changes were measured by comparing parent-reported scores of participants whose health did not alter to those who showed improvement. Two definitions of improvement in health included improvement in at least one category on the Social Responsiveness Scale (SRS-2) severity category and the Zarit Burden Interview (ZBI). These measures were selected for comparison based on observed correlations between domains of interest. The magnitude of change for each group was assessed using a paired t-test.

RESEARCH FINDINGS

Changes in baseline and endpoint scores were compared. The authors reported that a trend towards improvement was seen across all scales over the eight-week period. Participants showing improvements in autism severity based on SRS-2 showed improvements in core autism symptoms, social communication and restrictive repetitive behaviours. Participants showing improvements in overall burden based in ZBI showed improvements in restrictive repetitive behaviours, mood and anxiety, self-regulation and challenging behaviour. In both cases these effects were not observed in groups with no documented change or who had worsened.

IMPLICATIONS FOR PRACTICE (by the authors)

There was poor correlation between the ABI and ADOS. This suggests that ADOS, a tool designed to capture and evaluate the presence or absence of autism, may not be an effective tool to indicate changes in symptom severity over time.

ABI and ABI-S have the potential for use as one instrument in place of two or more alternatives in outcome studies.

The ABI-S shows good psychometric properties. The intention is to use this tool more frequently over the course of a clinical study to further reduce caregiver burden.

This study suggests that ABI is sensitive over time, which is in keeping with other clinical measures. Further studies on change over time is required to determine which version is most useful as an outcome scale measure.

Full Reference

Bangerter, A., Ness, S., Lewin, D., Aman, M.G., Esbensen, A.J., Goodwin, M.S., Dawson, G., Hendren, R., Leventhal, B., Shic, F., Opler, M., Ho, K.E. and Pandina, G., (2019). Clinical Validation of the Autism Behavior Inventory: Caregiver-Rated Assessment of Core and Associated Symptoms of Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. https://doi-org.libraryproxy.mic.ul.ie/10.1007/s10803-019-03965-7

CONCLUSION

Assessment can be considered from several different perspectives, formal and informal, assessment of a particular aspect of autism and assessment of autism for diagnostic purposes. All aspects of assessment are covered in the current Bulletin. There is considerable literature on the provision and development of interventions in autism; however, we are reminded in the current Bulletin that often interventions are only as effective as the prior assessment. Parents and professionals are advised to always link assessment to intervention and practice.

As discussed, assessment does not always need to be formal; it can be informal, but it must be pragmatic and related to the development of interventions. Parents and professionals across disciplines should be aware of new and existing assessments to fully support and plan for needs and strengths.

YOUR OPINION

The Centre trusts that you have found this Research Bulletin informative. It would be appreciated if you would take a few minutes to provide the Centre with feedback in relation to this bulletin by clicking on the survey link below.

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Assessment Practice in Autism

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