

Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers

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What is this report?

Who has this report been prepared for?

This report has been prepared for the National Disability Insurance Agency (NDIA).

Who has this report been prepared by?

It has been prepared by 2 consultants, with the assistance of 2 project officers, contracted by the NDIA.

To assist with the development of this report the NDIA also convened a stakeholder group (Textbox 2). At the time this report was produced, there had been 4 stakeholder meetings. Details are listed in Appendix 1. Meetings were a combination of face-to-face, phone and video meetings, using whichever mode best suited each stakeholder. It is anticipated that future stakeholder meetings will discuss this report along with the implementation of the report findings in the NDIA context.

What is the purpose of this report?

The NDIA sought to answer 3 questions (Textbox 1) to assist with making decisions about the delivery of services to preschool children with autism, and their families and other carers. The consultants were contracted to synthesise existing evidence, interpret it for the Australian context and recommend answers to questions 1-3.

Textbox 1 Questions posed for this report

- | | |
|-----------------|--|
| Question 1 (Q1) | What is evidence-based/evidence-informed good practice for supports provided to children with autism and their families/usual carers — with a focus on the autism-specific elements? |
| Question 2 (Q2) | What characteristics or other factors would assist in deciding individualised levels of early childhood intervention support needed for a child with autism? |
| Question 3 (Q3) | What factors, including intervention outcomes would indicate a need for a modification, for example an increase or decrease to intensity and/or type of intervention, once an early intervention program has been in place and the recommended timeframe for review of outcomes. |

Factors of relevance but beyond the scope of this report

The NDIS legislation sets out the eligibility criteria for entry into the scheme (NDIS Act 2013, S25) and the way this will be operationalised for early intervention is being decided as part of the trial period.

NDIA has commissioned Early Childhood Intervention Australia (ECIA) (<http://www.ecia.org.au/>) to develop good practice recommendations called 'National Guidelines for Early Childhood Intervention'. These recommendations will apply to all children, and will form the basis upon which specific recommendations focused on different types of developmental problems can be added.

Who is this report relevant to?

This report provides specific recommendations about children with autism and their families and other carers.

Textbox 2 The stakeholder group and their roles/positions

Dr Angelika Anderson	Senior Lecturer, Institute of Human Development & Counselling Krongold Centre, Faculty of Education, Monash University
Mr Bob Buckley	Convener, Autism Aspergers Advocacy Australia (A4)
Professor Anita Bundy	Professor & Chair of Occupational Therapy, Faculty of Health Sciences, University of Sydney
Professor Cheryl Dissanayake	Director, Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe University
Mr Barrie Elvish	Chief Executive Officer, Autism SA
Mr Adrian Ford	Chief Executive Officer, Aspect Australia
Ms Kathryn Fordyce	Manager, North West Tasmania Autism Specific Early Learning and Care Centre (Burnie City Council)
Professor Deb Keen	Autism Centre of Excellence, School of Education and Professional Studies, Griffith University Mt Gravatt Campus
Ms Denise Luscombe	National President. Early Childhood Intervention Australia
Ms Sylvana Mahmic	Vice President, Early Childhood Intervention Australia Chief Executive Officer, Plumtree
Ms Joan McKenna-Kerr	Chief Executive Officer, Autism Association of Western Australia
Professor Sylvia Rodger	Director of Research and Education, Australian Learning and Teaching Fellow (Office of Learning and Teaching), Autism CRC Ltd, Cooperative Research Centre for Living with Autism Spectrum Disorders
Mr Alan Smith	Chief Executive Officer, AEIOU Foundation
Professor Andrew Whitehouse	Head of Developmental Disorders Research Group, Telethon Kid's Institute, University of Western Australia

Abbreviations

ABA	applied behaviour analysis
ADHD	attention deficit hyperactivity disorder
ADOS	Autism Diagnostic Observation Schedule
AHRQ	Agency for Healthcare Research and Quality
ASD	autism spectrum disorder
CTM	comprehensive treatment models
DSM-5	Fifth Edition of Diagnostic and Statistical Manual of Mental Disorders
EBP	evidence-based practice
ECI	early childhood intervention
ECIA	Early Childhood Intervention Australia
FaHCSIA	Australian Department of Families, Housing, Community Services and Indigenous Affairs
ICD-10	International Statistical Classification of Diseases and Related Health problems (10th revision)
NAC	National Autism Centre
NDIA	National Disability Insurance Agency
NICE	National Institute for Health and Care Excellence
PECS	picture communication exchange system
PRT	pivotal response therapy
RCT	randomised controlled trial
SR	systematic review
UCLA Lovaas	University of California, Los Angeles Lovaas Approach

Executive summary

Purpose

The National Disability Insurance Agency sought answers to 3 questions about the provision of early intervention for children with autism.

Diagnosis of autism, as described in existing guidelines, requires children to be assessed by a paediatrician or a child and adolescent psychiatrist, a psychologist and a speech pathologist and for a consensus diagnosis to have been reached in accordance with existing classification systems. Current classification systems are The Diagnostic and Statistical Manual of Mental Disorders: DSM-5 or the International Classification of Diseases and Related Health problems, 10th edition (ICD-10). Also recommended is consideration be given to detailed profiling of strengths and difficulties, beyond what may be needed for making a diagnosis, to enable tailoring of intervention and management strategies. If DSM-5 is used, the severity of ASD symptoms and level of functioning should be specified along with the presence of co-morbid conditions.

Methods

Information to answer the 3 questions posed was gathered from systematic reviews and evidence-based guidelines that had been published after the evidence summary prepared for FaHCSIA in 2011. Following feedback from the stakeholder group the review was broadened to include information from reviews that included single case studies and a 'consensus statement' about up-to-date approaches to support and early intervention for preschool children.

The systematic reviews, guidelines and good practice statements that were included are listed in **Error! Reference source not found..**

Recommendations relevant to Questions 1-3 were extracted from these reports and a narrative synthesis conducted to identify emergent themes of what constituted good practice.

Table 1 Systematic reviews and guides that were included in this review

Full reference	Abbreviation used
National Autism Center (NAC) (2015). <i>Findings and conclusions: National Standards Project, Phase 2</i> . Retrieved from http://www.nationalautismcenter.org/national-standards-project/phase-2/	NAC, 2015
National Collaborating Centre for Mental Health (2013). <i>Autism. The Management and Support of Children and Young People on the Autism Spectrum</i> . London (UK): National Institute for Health and Care Excellence (NICE). Retrieved from http://www.nice.org.uk/guidance/cg170	NICE guidelines, 2013
Prior, M. & Roberts, J. (2012). <i>Early Intervention for Children with Autism Spectrum Disorders: 'Guidelines for Good Practice'</i> . Retrieved from https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/early-intervention-for-children-with-autism-spectrum-disorders-guidelines-for-good-practice-2012	Prior & Roberts, 2012
Schreibman, L., Dawson, G., Stahmer, A. C., Landa, R., Rogers, S. J., McGee, G. G., & Halladay, A. (2015). Naturalistic Developmental Behavioral Interventions: Empirically Validated Treatments for Autism Spectrum Disorder. <i>Journal of Autism and Developmental Disorders</i> , 1-18.	Schreibman et al., 2015
Weitlauf AS, McPheeters ML, Peters B, Sathe N, Travis R, Aiello R, Williamson E, Veenstra-VanderWeele J, Krishnaswami S, Jerome R, Warren Z. <i>Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update. Comparative Effectiveness Review No. 137</i> . Rockville, MD: Agency for Healthcare Research and Quality; 2014.	Weitlauf et al., 2014
Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fettig, A., Kucharczyk, S., ... Schultz, T. R. (2014). <i>Evidence-based practices for children, youth, and young adults with Autism Spectrum Disorder</i> . Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.	Wong et al., 2014

Question 1

What is evidence-based/evidence-informed good practice for supports provided to children with autism and their families/usual carers — with a focus on the autism-specific elements?

Findings

Several key support elements were identified from the included reviews and publications. We developed a structure for describing these key support elements, aware that elements listed interact with one another on the pathway to finding the right evidence-informed good practice supports for each individual child and family. The key support elements and their subcategories were grouped as shown in Table 2.

Table 2 Key support elements underpinning and informing good practice in early intervention for autism

Key support elements	Subcategories
Underpinning principles	Evidence-based Families require support Family-centred Individual planning
Aims, approaches and strategies	Aims: Social communication development Minimise behaviours that challenge Enhance learning and participation Approaches: Environmental management Building on opportunities Antecedent – behaviours – consequence Transition support Strategies (for details see Table 3)
When, who, and where?	When to start Team approach Setting and staff ratios Professional development and training Parent training and development Peer interventions
Intervention programs	Program requirements: Intensity Quality Delivery Evaluation Program types
Other considerations	Co-occurring or related conditions Capacity building

Key findings were:

- Parents/carers of children with autism should be supported during the early intervention years.
- Supports for children with autism should be evidence-based and delivered using a family-centred approach that incorporates individual planning.
- The specific early intervention program chosen will take into account family preferences and capacity and each child's strengths and difficulties, age and stage of development.

- Aims of support for the child with autism are to improve social communication and minimise behaviours that challenge to enhance learning and participation.
- Approaches recommended are environmental modification, building on opportunities and supporting transitions.
- A large number of evidence-based strategies can be used to achieve these aims.
- Early intervention or support should start as soon as a diagnosis is made and the family are ready.
- Having well-trained professionals working as teams to support children with autism and their families is needed. Parent or peer training is promoted, as long as it is incorporated to take into account a family-centred approach.
- Intervention programs for children with autism should be comprehensive, that is, across all domains of learning, with clearly stated, replicable process and content. This type of program can be one that has been developed and given a name, such as Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) and the Early Start Denver Model (ESDM), or one that is developed for an individual child through an individual planning process designed to identify and achieve agreed aims, using good-practice principles and evidence-based strategies, sometimes called an eclectic comprehensive intervention program. For example components of a comprehensive program may focus on the development of communication, the management of problem behaviour and the understanding of emotions. Components of a comprehensive individualised program may also be named evidence based strategies, such as Picture Exchange Communication System (PECS), or based on evidence based approaches, such as Positive Behaviour Support (PBS).
- Early intervention programs for children with autism must be of sufficient intensity and fidelity (i.e. implemented consistently and accurately) and be evaluated to ensure program quality.
- Interventions identified as (1) proven not to be effective or (2) without evidence that they are effective should not be used.
- Difficulties that may co-occur with autism or present in a similar way, but need separate diagnosis and specific or targeted interventions, should be considered.

Recommendations

1. Key elements as outlined above be included in all support for young children with autism and their families
2. Programs offered to children and their families be assessed to ensure that they include these key elements
3. Further work be done to develop decision supports for families so they can take these key elements into account, for example deciding on the setting for their child's intervention, and prioritise goals for their child and family
4. Interventions that are not recommended (NICE guidelines, 2013) or listed as not evidence-based (NAC, 2015) should not be offered.

Question 2

What characteristics or other factors would assist in deciding individualised levels of early childhood intervention support needed for a child with autism?

Findings

The level of early intervention support is a funding (or package) decision made prior to the commencement of a support program being implemented. Even if, as is ideal, detailed information about an individual child and family's strengths and difficulties is available to those making this decision, there is not yet sufficient evidence upon which to base individualised decisions about the level of early intervention support for children with autism based on these characteristics.

Current best evidence to inform decisions about level of support is information about intensity and duration of interventions that have been shown to be effective. Reviews and guidelines that provide evidence about intensity (hours per week) and duration of interventions report that comprehensive programs that have been evaluated and shown to be effective are most commonly provided for between 15 and 25 hours a week, suggesting a midpoint of 20 hours, and for at least 1 year. Children included in the studies that have been reviewed have a diagnosis of autism (research standard).

There are notable gaps in the evidence. In particular the recommended ratio of allied health professional time to other appropriately trained therapists/early intervention workers and the proportion of time that should be spent in 1 staff:1 child versus small groups (up to 1:3) settings was not easy to distil from existing literature. In addition, from a practical standpoint the amount, type and ratio of staff:child intervention is related to the strengths and needs, age and stage of the child and the goals of the child's program. For example work on some communication goals can only be done in a small peer group setting.

Factors, other than evidence about intervention effectiveness, that need to be taken into account when making decisions about the level of support for young children, include ethical and equity considerations, and also the way parents adjust and adapt to their child and their individual needs.

Recommendations

Children who have received a diagnosis of autism should receive 20 hours per week of early intervention that involves interaction with them. Review of progress should occur by the early intervention support program team as outlined in Q 3, with review of the level of support annually, unless earlier review is indicated. In addition a package to support the child's family (for example, counselling or assistance arranging child care) be provided.

The level of support comes with requirements that:

1. the support for the child and family fulfils specifications provided in Q1. In particular:
 - staff to child ratios can vary between 1:1 and 1:3 as determined by the child's individual program
 - all staff are autism trained (training and qualifications will vary)

- programs must involve allied health professionals in individual planning, program implementation and review
2. the support is sufficiently flexible that it can be adapted and modified in line with the child and parents' strengths and needs (see Q 3).

Following an allocation of support parents will need support to choose the most appropriate type of intervention for their child, their situation and their preferences, and also to identify their family's support needs.

Whether this recommendation is feasible in Australia today is outside the scope of this report.

Question 3

What factors, including intervention outcomes would indicate a need for a modification, for example an increase or decrease to intensity and/or type of intervention, once an early intervention program has been in place and the recommended timeframe for review of outcomes?

Findings

The heterogeneity of autism, variability of development over time of children with autism and the understanding that no one intervention will meet the needs of all children with autism, reinforces the need for individualised planning for each child with autism and their family.

In addition the evidence is not yet clear which interventions work best for which children with autism. Interventions vary in their content, ways of teaching, and the skills and attributes of those who teach and train young children with autism and support their families. The goals for children, their families and their interventionists are also variable. In addition the way parents/carers value different outcomes also differs from one family to the next and will be influenced by their child's age and stage. For example the priorities of families with newly diagnosed children will be different from those of children making the transition to school a year or 2 after diagnosis.

Intervention programs need to be evaluated regularly to ensure that they continue to meet the needs of the child. This process involves a review of the individual plan goals and review of the child's skills and needs to ensure that the program is addressing both of these. For example at review whether a child is showing improvement will be noted as well as whether the goals are still relevant. Individual plans should be developed at least annually and reviewed at least every 6 months (Prior et al., 2011, p123).

Currently there is insufficient evidence about what factors indicate a need for a modification to early intervention programs to allow evidence-based decisions for individuals based on well-described subgroups or characteristics, such as age and ability. Therefore there is a need for individualised planning that provides information that is needed to make decisions about support/funding level. As such the early intervention support team will be required to review progress and develop a program that meets the child and family's needs and provide information about intensity, staffing type, staffing ratios and setting.

Recommendations

For the NDIA planner

The planner will review the child/family plan every 12 months to determine if continuation of support is needed.

The planner will review the individual plan created by the early intervention support team who have been providing services for the child and family for the previous 12 months. This will be done in collaboration with the family and relevant professionals to assess the suitability of the intervention provided for the child and family with consideration given to factors outlined in Q1 and Q2.

The planner's review should include review of child and family factors, changes, priorities, review of long term goals, resources, strengths and needs.

The planner will make recommendations about any changes required in the child's plan including level and broad types of support required for the next 12 month period.

Planners will require professional development so that they know what a good plan and a relevant review looks like.

For the program support team

Program teams will focus on a collaborative, functional assessment, goal setting, plan implementation with review and revision at least every 6 months, as per the recommended individual planning process. Available resources, such as the Positive Partnerships Planning Matrix and Goal Attainment Scaling, may be used to assist with this.

Review by the program team will:

1. allow timely modification of support based on changes — either improvements or failure to respond to intervention, or new difficulties — in relation to the approaches and actions being used for early intervention, the location and the people involved
2. allow information sharing with those who allocate funding (packages) to ensure the appropriate level of funding is available for the child and family
3. demonstrate early intervention supports are being offered in a way that is consistent with good practice.

Every 12 months the individual plan will be shared with the NDIA planner and information including:

1. intensity of the program required
2. staffing type
3. staffing ratios
4. setting(s) for early program
5. amount of support needed for the family, and how this will be delivered

Recommendations for best practice and research

We propose that to achieve best practice and fill existing evidence gaps:

1. An individual plan is created for each child based on current good practice as set out in Q3.
2. The individual plan includes goals and a method to assess goal achievement — outcome measure(s).
3. Parent involvement in developing the individual plan, including outcomes, is documented.
4. The individual plan includes the type(s) of intervention being used and rationale for selection of intervention.
5. The individual plan be reviewed at least every 6 months, or more frequently if great gains are made, there is minimal or no response to intervention, or new difficulties are identified.
6. Outcomes are measured at least every 6 months to assess goals.
7. An assessment of adaptive behaviours and also an assessment of social communication be completed at least every year — as indicators of progress in key areas addressed by early intervention.
8. Early intervention services provide the names, qualifications and experience of their early intervention professionals to NDIA.
9. NDIA is notified as to whether a key worker was assigned to a child and who they are, if one was assigned.
10. Early intervention professionals keep a record of their early intervention encounters with each child, including information about:
 - a. number of face-to-face hours with the child per week
 - b. whether the encounter was one-to-one or group based, and if group based the ratio of professionals to children
 - c. the setting in which the intervention occurred
 - d. whether a parent/carer or childcare worker was being trained.
11. Information is gathered from parents/carers about their experience of the interventions offered.
12. Information is sought from parents of children with autism to understand their preference for and experience of parent engagement in early interventions offered.
13. Information is collected about parent/carer health and wellbeing.
14. Information is collected about any additional services accessed by the child and family.

Planning for use of agreed mechanisms for monitoring outcomes over time is needed to optimise the tailoring of individual plans for early intervention and support and to enable effective targeted service planning, development, implementation, review and revision.

Definitions and terms used

Aims of supports

All autism interventions aim to improve social communication and minimise behaviours that challenge on the pathway to improving learning and participation for each child with autism and their family.

Approach to supports

Different approaches (also known as processes) to delivering intervention exist. The autism field is not consistent in how it talks about this. So we are separating the approach from the strategy or action (see below) aware that different terms are used and that approach and strategies are often combined in lists of effective interventions presented in other documents. In one review (Wong et al., 2014) the term ‘focused interventions’ was used (see below) for interventions that vary in terms of who delivers them, the intervention approach and the specific type of actions that are taken to achieve a specific goal (e.g. development of communication abilities). Comprehensive intervention programs (see below) similarly are developed taking into account the ‘who delivers the intervention’, aims, approach, however in comprehensive programs, strategies with individual modifications are made *within the framework of the program*. Intervention may also be based on individual planning, goals and strategies and not necessarily incorporate named programs, that is, developed with the ‘who delivers the intervention’, aims, approach and strategies as key components of an individualised plan.

Autism

In this document the word autism will be used for Autism Spectrum Disorder (DSM5) and all autism spectrum disorders (ASD) (DSM-IV & ICD-10).

Comprehensive intervention programs (also known as comprehensive treatment models)

Comprehensive programs ‘consist of a set of practices designed to achieve a broad learning or developmental impact on the core deficits of ASD’ (Wong et al., 2014). ‘These programs were characterised by organisation (i.e., around a conceptual framework), operationalisation (i.e., procedures manualised), intensity (i.e., substantial number of hours per week), longevity (i.e., occur across 1 or more years), and breadth of outcome focus (i.e., multiple outcomes such as communication, behavior, social competence targeted)’ (Wong et al., 2014).

Early childhood intervention

‘ECI is the process of providing specialised support and services for infants and young children with developmental delays or disabilities (aged from birth through to school age), and their families in order to promote development, wellbeing and community participation. The aim of these services is to work in partnership with parents, families and significant others to enhance their knowledge, skills and supports to meet the needs of the child, optimise the child’s learning and development, and their ability to participate in family and community life. One of the most influential shifts in ECI

has been the move from a focus on attempting to address children's "deficits" or "impairment" to a focus on promoting participation and highlighting the whole context of development within the home and the community.' (taken from the *Early Intervention Best Practice discussion paper* available at <http://www.ecia.org.au/documents/item/114>)

Evidence-based

By evidence-based we mean interventions that have been through a process of evaluation that has proven that they improve child functioning in the specific domains which are being treated, such as social, communication and adaptive behaviour. Gathering and synthesising evidence requires the use of a standard set of rules for study inclusion and evaluation, which have been agreed to by scientists in this field. There is a lack of consistency in the way evidence about autism supports and interventions is gathered and assessed. The main difference is that some systematic reviews/guidelines require group based comparative studies as the minimum level of evidence and others accept single-case design studies. This leads to differences in the way included studies are assessed and how evidence is synthesised, and also to differences in findings.

In this review we have been inclusive of all research-evaluating approaches as long as the rules for inclusion and evaluation are clear and agreed to by those working in the field. This does not mean, however, that all evidence is equal. Some research evaluating some approaches, included in systematic reviews/guidelines is not of sufficient rigor to allow us to be sure that there is improvement beyond that which would occur over time, or as a result of an alternative (comparison) intervention.

Focused interventions

Focused interventions are 'designed to address a single skill or goal of a student with ASD' (Odom et al., 2012). These practices are operationally defined, address specific learner outcomes, and tend to occur over a shorter time period than comprehensive treatment models (i.e., until the individual goal is achieved). 'Examples include discrete trial teaching, pivotal response training, prompting, and video modelling.' (Wong et al., 2014).

'Focused intervention practices could be considered the building blocks of educational programs for children and youth with ASD, and they are highly salient features of the Comprehensive Treatment Models (CTMs)' (Wong et al., 2014).

Guidelines

Guidelines are developed to provide advice or recommendations about best practice. Guidelines incorporate evidence from systematic reviews and other sources and usually provide an assessment of the level of evidence upon which each recommendation is based, so the reader has an understanding of whether that recommendation is likely to change if/when new evidence emerges.

Multi-disciplinary, Transdisciplinary, Interdisciplinary

These terms are used in different ways by different people. In this report we will not use these terms but will instead describe in brief phrases what we mean in the relevant situation so that it is clear what is needed. We will use the term 'team' when well-coordinated care is needed with more than one type of professional expertise.

Parents

In this document the term parents will be used for parents and others who provide care for the child in their everyday life, including for example, step-parents, foster carers and grandparents.

Preschoolers

In this report *preschoolers* includes children before they go to school and up to the age of 8, in line with the *Early Intervention Best Practice discussion paper* (available at <http://www.ecia.org.au/documents/item/114>).

Strategies

Different specific intervention types are used to support children with autism, and can be delivered in different settings and by different individuals. These have been called procedures by some, but terminology in the literature varies. Examples of strategies potentially used in early intervention are imitation and modelling.

Supports provided to children with autism and their families/usual carers

This phrase is used in Q1 and indicates early intervention for children with autism and broader assistance beyond the definition of early childhood intervention. *Supports* was chosen as the preferred phrase for Q1 by the stakeholder group.

Systematic reviews of interventions

A systematic review is a review which follows pre-determined methods for searching the literature, evaluating evidence found and synthesising the evidence. The aim of a systematic review is to minimise bias that can be created by presenting only part of the existing evidence base, and also to provide the reader with information about the risk of bias or quality of included studies and overall strength of the evidence found. Based on the methods used, a summary or synthesis, statistical if possible, is provided so the reader has relevant information about the efficacy or effectiveness of the intervention(s) investigated.

Where intervention occurs

Interventions can occur in the home, community, childcare facilities, educational settings, specialised autism centres, specialised early intervention centres or a combination of these.

Who delivers an intervention

Interventions can be delivered by professionals, parents/carers and siblings/peers. Most commonly the professionals involved are psychologists, speech therapists (also known as speech pathologists and speech and language therapists/pathologist (SLP)), occupational therapists, social workers, teachers, childcare workers, and therapists trained to deliver a certain type of intervention, for example behaviourists. Parents and other carers for a child also deliver intervention, as do their peers or siblings, when trained.

Background information

Autism today

Much is still to be learned about the early years of development for children with autism. While research and science continue to strive to provide a comprehensive understanding of the underpinnings of autism and its characteristics, along with the best ways to prevent, ameliorate or manage them, families require services that are based on the best of what we know already. Unfortunately the autism world is no stranger to controversy and historically there have been claims about causes and interventions reported to provide impressive outcomes that have later been disproven. Also named and marketed interventions and intense competition between different service providers adds to the confusion. This landscape of ongoing discoveries about cause, new understandings about autism, both how to diagnose it and best interventions, coupled with a lack of agreement about what constitutes best intervention and management is hard for parents, carers, service providers, service developers and policy makers to navigate.

What we do know is that all children with autism have difficulties with social communication and restricted or repetitive behaviours, for some including sensory problems that are out of keeping with children of a similar ability. Children with autism also commonly have other developmental, emotional or behavioural problems, including anxiety, intellectual disability and attention deficit hyperactivity disorder (ADHD). Autism 'is a neurodevelopmental disorder beginning at birth or shortly after. ... To help children with autism it is essential to focus on the earliest years of development, since this is a critically important time for early learning which powerfully affects the child's future life course' (Prior & Roberts, 2012).

Diagnosis

There are now established recommendations for diagnosis and assessment of children with autism from Australia (Silove et al., 2008) and internationally (NICE guidelines, 2013).

All diagnosis and assessment guidelines require children to be assessed by a paediatrician or a child and adolescent psychiatrist, a psychologist and a speech pathologist and for a consensus diagnosis to have been reached in accordance with existing classification systems, which for children today will be the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) or the International Classification of Diseases and Related Health problems, 10th edition (ICD-10). All recommend that consideration be given to detailed profiling of strengths and difficulties, beyond what may be needed for making a diagnosis, to enable tailoring of intervention and management strategies. Under DSM-5, the severity of ASD symptoms and level of functioning should be specified along with the presence of co-morbid conditions. Information about the child and family from the diagnosis and assessment process can then be used to guide the selection of autism-specific approaches to intervention, that are in line with current best evidence and parents priorities, that are most likely to be successful.

Support and interventions

Autism is a highly variable condition, which changes over time as children grow and develop. As a result even interventions and strategies with the most robust evidence will not be effective for all children with autism all the time. The NAC (2015) acknowledges that while it is important to consider research-based interventions first, there are additional criteria to be considered when selecting interventions. For example the NAC (2015) states that individual preferences and values, capacity, and professional experience also play a role in intervention selection. This is often referred to as evidence-based practice (EBP). In this environment parents and their collaborating professionals need guidance about the key elements of good practice in ASD intervention, to inform their decisions about interventions that are likely to be most effective and appropriate for their situation. Nonetheless evidence-based or -informed guidance is very important in the field of autism, because there has been high uptake of interventions that lack scientific evidence for effectiveness, some of which have caused direct harm to children.

All interventions have potential negative impacts

All interventions have potential negative effects, and early intervention is no exception. Information about negative effects has rarely been reported and this is mentioned specifically in 2 reports (Weitlauf et al., 2014; NAC, 2015). As well as direct negative effects, there are opportunity costs if ineffective supports and interventions are used.

Individual difference

We know that no 2 children with autism are the same, which means that interventions will need to be adapted to suit each child's autism characteristics, their abilities, their environment and their parents' priorities and values.

The way children with autism change and develop over time is not predictable. For example development in some children with autism may appear to plateau for a time. Some children with autism may even regress. As a result information about their progress, new characteristics and emerging abilities or difficulties is also necessary to tailor interventions on an ongoing basis to the needs of a child and their family.

Evidence about autism is evolving

Evidence that underpins guidance about supports for preschool children with autism and their families continues to evolve. It is likely that our understanding of best practice for support and intervention will also be influenced by changes in our understanding of autism and its causes, which will be linked in turn to best methods for diagnosis. This means that any recommendations provided will need to be updated as new evidence emerges or as reviews and guidelines based on evidence are published, for example a NICE guidelines update is expected in 2016.

Methods

The methods proposed and accepted by the stakeholder group and the NDIA for this review can be found in Appendix 2. The methods used, as presented in an interim report, are presented in Appendix 3.

In brief, systematic reviews and evidence-based guidelines relevant to support and early intervention for children with autism, including any of the subcategory diagnoses that are included in the autism spectrum, were included, with a focus on children aged up to 8 years. The academic literature and relevant autism and government websites were searched, with a focus on publications and reports from 2011. The project officers (KS & LC) presented key findings from publications and reports identified and the consultants assessed findings for relevance and synthesised key messages. These were shared with the stakeholders as an interim report (Appendix 3) and stakeholders were asked to suggest additional missed resources and whether input from a broad expert groups was needed.

Results and description of evidence records

Two sources of information, the NICE guidelines (<https://www.nice.org.uk/guidance/cg170>) and quality standards (<https://www.nice.org.uk/guidance/qs51>) for autism, and the Agency for Healthcare Research and Quality (AHRQ) 'Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update' (Weitlauf et al., 2014, retrieved from <http://effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?productid=1945&pageaction=displayproduct>) emerged as authoritative sources because they were well conducted reviews, contained relevant information, and were comprehensive and up-to-date.

Stakeholder feedback directed the reviewers to a recently published report that contained detailed information about evidence-informed specific early intervention strategies for experts to use and made some recommendations for evidence-based practice (NAC, 2015). Stakeholder feedback also recommended further consideration and incorporation of a current paper (Schreibman et al., 2015) representing a consensus statement about early intervention in autism from experts in the field. The consultants also decided to include a systematic review of focused interventions for autism (Wong et al., 2014). In addition, given this report was designed to build on the earlier work completed in Australia, the guidelines provided (Prior & Roberts, 2012) was also reviewed and incorporated.

All recommendations for evidence-based / -informed support and relevant principles that were included in these reports were extracted and grouped by the consultants to develop key principles. Specific intervention practices, either comprehensive or focused, that were reported as evidence-based were also extracted and lists compiled. Lists of practices that were reported as not evidence based that were accompanied with instructions about how to use the lists in practice, were also compiled.

Of the sources of information included one is a guideline (NICE guidelines, 2013) which is underpinned by a systematic review and evidence synthesis and evaluation. The full NICE guidelines

(2013) provide information about methods used to develop the guidance and assessment of included evidence. Three were systematic reviews and syntheses (NAC, 2015; Weitlauf et al., 2014; Wong et al., 2014). All syntheses used different methods for inclusion of studies and evaluation of the quality and/or strength of evidence.

One review identified evidence-based 'focused intervention practices' (see definition above) (Wong et al., 2014) with another identifying similar practices that they called 'procedures' (NAC, 2015) as well as comprehensive intervention programs. Both of these reviews included single-case design studies as well as controlled studies. The others included only group interventions studies that included a comparison group (NICE guidelines, 2013; Weitlauf et al., 2014). The AHRQ report (Weitlauf et al., 2014) sets out to answer specific questions while the NICE guidelines (2013) were developed for a broad age-group of children and young people with autism, and their families.

One review, that did not use systematic review methodology or assess the level of evidence of included studies, but brought together many experts in the field to form a consensus statement was also used as a source of best practice suggestions (Schreibman et al., 2015), as was the only other local guidance about best practice in autism (Prior & Roberts, 2012).

The NICE guidelines (2013) evidence was last searched for in January 2013. The other reviews last searched for evidence on the following dates: Weitlauf et al., 2014 - December 2013; NAC, 2015 - Feb 2012; Wong et al., - Dec 2011; Prior & Roberts - 2012.

Contact with experts was not pursued following mixed feedback from the stakeholder group.

Question 1. Good practice

What is evidence-based/evidence-informed good practice for supports provided to children with autism and their families/usual carers — with a focus on the autism-specific elements?

Several key support elements were identified from the included reviews and publications, albeit with different requirements for good practice identified from different publications (Appendix 4). We have developed a structure for describing these key support elements, aware that elements listed interact with one another on the pathway to finding the right evidence-informed good practice supports for each individual child and family.

Underpinning principles are that the parents/carers of children with autism should be supported during the early intervention years. Supports for children with autism should be evidence-based and delivered using a family-centred approach that incorporates individual planning. The specific early intervention program chosen will take into account family preferences and capacity and each child's strengths and difficulties, age and stage of development.

Aims of support for the child with autism are to improve social communication, enhance learning and participation and minimise behaviours that challenge. . Approaches recommended are teaching specific skills, environmental modification, building on opportunities and supporting transitions. A large number of evidence-based strategies can be used to achieve these aims and are aligned with overarching approaches.

Early intervention or support should start as soon as autism is diagnosed and the family is ready. Having well trained professionals working as a team to support the child with autism and their family is needed. Parent or peer training is promoted, as long as it is incorporated to take into account a family-centred approach.

There are key elements that are necessary for intervention programs for children with autism. Programs must have sufficient intensity, fidelity and be evaluated to ensure program quality. Support or intervention programs are either comprehensive (across all domains of learning) named interventions or comprehensive programs developed through individual planning that work towards achieving the agreed aims, using good-practice approaches and evidence-based strategies. The latter are sometimes called eclectic comprehensive programs.

Some interventions were also identified as proven to be not effective or as lacking evidence that they are effective. These should not be used. Other considerations included identification of difficulties that may co-occur with autism or present in a similar way, but need separate diagnosis and specific or targeted interventions.

Underpinning principles

Evidence-based

The NAC (2015) review provides specific guidance about how to use the interventions it describes as either evidence-based or emerging. Some interventions are described as unestablished and are not recommended for use at all. Essentially the NAC (2015) recommendation is to use established evidence-based interventions or strategies. If unsuccessful or inadequate to meet goals then consider emerging interventions. Do not use unestablished interventions until evidence for their efficacy or effectiveness is available. Regularly review the evidence, and adapt practice by including interventions and strategies as evidence for their efficacy or effectiveness becomes available.

Families require support

All families with a child who has been newly diagnosed with autism will require support for themselves in addition to support that is provided for their child. Supports for families should address need for emotional support, for example by provision of parent support groups, and also the need for respite for all family members. Access to respite for families should be facilitated as required. All families will experience fluctuations in their support requirements depending on events and their personal circumstances. The level of support that is available should be able to be adjusted to accommodate these changes. Times when additional support is highly likely to be required include transition to school, time of important changes at home and any time intervention is implemented but is not effective or has undesirable side effects.

Family-centred

The following practices were considered necessary:

- Provide families with information about autism, its management, available services, relevant to the age and stage of their child.
- Provide assessment for child and family as required, needs, strengths, resources and preferences.
- Consult with families about the extent they wish to be involved in decision making and program development and offer partnership to the extent they prefer.
- Take account of family resources, capacity (time, money, stress) when selecting an intervention.
- Consider the values and preferences of the family and the person with autism when choosing an intervention and respect their wishes should they not wish to proceed with an intervention.

Individual planning

Children with autism have highly variable profiles of characteristics and different needs. An individual plan is required to address these characteristics and ensure planned interventions are appropriate to the age and stage of the child. Characteristics can be strengths as well as needs, and strengths can be developed and utilised to compensate for difficulties. Families and environments also vary in their strengths (resources) and needs and this must be taken into account when planning. Engagement with families and other key people in a child's life is essential when developing an intervention program. Assessment of individual child, family, and environment with a

focus on adaptive functioning is essential. Plans should include goals for intervention, strategies, and methods for data collection and review, as further described below in the quality section.

Aims, approaches and actions

Aims

Choice of intervention(s) should be based on needs of the child and 'address core issues such as engagement and joint attention while systematically improving specific communication, cognitive and other skills' (Schreibman et al., 2015) and aimed at enhancing function and adaptive behaviour.

Social communication development

There should be a focus on the development of social communication, reciprocity and engagement and also on increasing communication partner understanding and responsivity (see also parent/carer training).

Minimise behaviours that challenge

Minimising behaviour that challenges can increase learning and participation opportunities. Before using approaches to encourage positive behaviours or other interventions, ensure there is no mental health, environmental (see below) or physical problem triggering or maintaining the behaviour.

Enhance learning and participation

As social communication improves and behaviours that challenge are minimised it is important to encourage development of independent functioning and practical skills that will further enhance participation and learning opportunities.

Approaches

Environmental management

Environmental management refers to the structuring of the environment to facilitate child initiation and interaction with others, and also to manage characteristics of autism, such as sensory characteristics and resistance to change. Environmental management potentially provides a supportive teaching environment, visual supports, structure and routine, and caters to personal space requirements, management of obsessions and rituals, and sensory issues. Environmental management should be individualised and provided as determined by the child's program.

Building on opportunities

Strategies that are relevant to the child's age and stage and build on existing repertoire and social routines are ideal. Schreibman et al. (2015) refer to the use of child initiated teaching episodes, also referred to as following the child's lead or interest or child choice, which increases the child's engagement and motivation and provides naturally occurring reinforcement of learning. Use of naturally occurring contingencies as well as teaching activities that capitalise on child motivation are ideal. This could include incorporating obsessions and rituals to engage a child and reinforce responses. In young children strategies should be predominantly play based.

Naturalistic teaching strategies, listed as evidence based in the NAC (2015) review, is one approach that builds on opportunities to increase adaptive skills. Naturalistic teaching strategies 'are a compilation of strategies that are used to teach children skills in their home, school, and community.

The basic concepts include using materials in the environment and naturally occurring activities' (NAC, 2015). Similarly pivotal response training or Pivotal Response Treatment®, which is listed as a strategy below 'focuses on targeting "pivotal" behaviors related to motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues' (NAC, 2015). Pivotal response training or treatment (PRT) includes parents and focuses on implementation in the natural environment, such as the home or in community or childcare settings.

Antecedent – behaviours – consequence

All interventions should 'utilize a 3-part contingency (antecedent-response (behaviour)-consequence) to help the child understand when to respond and to provide feedback to the child' (Schreibman et al., 2015).

When developing an intervention for behaviour that challenges, first assess potential antecedent factors such as, communication difficulties, unpredictability, physical problems, the physical and social environment, changes to circumstances and routines, and possible abuse. Take into account the nature, severity and impact of the behaviour, the child's communication needs, the environment, preferences of the child and their family or carers, prior experience and response to interventions and necessary supports or training for the family or carers. Focus on proactive strategies to address triggers including management of the environment (see below). Teach alternative appropriate skills including communication skills. Consider functional behaviour analysis if behaviour persists.

Transition support

Specialised support for major transitions such as into preschool and into school is essential for children with autism. Children with autism are typically very resistant to change. They may also need support to manage daily transitions as they struggle to maintain predictability.

Strategies

Evidence based strategies that are relevant include imitation, modelling and video modelling/feedback, and also verbal, visual, or physical prompting (also known as scaffolding or cueing) to support behaviour not yet established and provide opportunities for reinforcement and learning (see others in Table 3). The NAC (2015) review also identified evidence-based behavioural interventions that were used either alone or in combination (Appendix 5), and listed strategies with an emerging evidence base that were not proven to be effective at the time the report was published (Appendix 6).

Table 3 Strategies that are listed in one or more review or publication as evidence-based for preschool aged children

Strategy (age group if listed in review or publication)	Review*
Antecedent-based intervention	Wong et al.
Behavioural interventions alone or in combination (see Appendix 5) [#]	NAC
Cognitive behavioural intervention (6yrs and older)	NAC, Wong et al.
Differential reinforcement of Alternative, Incompatible, or Other Behaviour	Wong et al.
Discrete trial teaching	Wong et al.
Exercise [^]	Wong et al.
Extinction	Wong et al.
Functional behaviour assessment	Wong et al.
Functional communication training	Wong et al.
Language Training (Production) (3–9)	NAC
Modelling (3–18)	NAC, Wong et al.
Naturalistic intervention	Wong et al.
Play based social communication for young children	AHRQ
Picture exchange communication system	Wong et al.
Pivotal response training [†]	NAC, Wong et al.
Prompting	Wong et al.
Reinforcement	Wong et al.
Response Interruption/Redirection	Wong et al.
Story-based Interventions (3–14)	NAC
Scripting (3–14)	NAC, Wong et al.
Schedules (3–9)	NAC
Self management	Wong et al.
Social narrative	Wong et al.
Social skills training ^{††}	Wong et al.
Task analysis	Wong et al.
Technology-aided instruction and intervention [^]	Wong et al.
Therapist modelling and video-interaction feedback for play-based social communication strategies with parents, carers and professionals	NICE
Time delay	Wong et al.
Video-modelling	Wong et al.
Visual supports	NICE, Wong et al.

* Reviews are : Wong et al. = Wong et al., 2014; NAC = NAC, 2015; AHRQ = Weitlauf et al., 2014; NICE = NICE guidelines, 2013.

[#] some included in table as listed separately in Wong et al.

[^] emerging not evidence based in NAC

[†] listed as Pivotal Response Treatment ® in Wong et al.

^{††} discussed mainly offered for school aged children with IQ > 70 in AHRQ report

When, who, and where?

When to start

It is generally agreed that early intervention should commence as soon as autism is diagnosed. Evidence suggests 'younger age was associated with greater improvements, though effects were not always consistent' (Weitlauf et al., 2014).

Team approach

Programs to be developed, implemented and reviewed by a collaborative team including professionals, such as speech pathologists, psychologists, doctors, social work or mental health professionals, teachers, as well as families and the person with autism. To facilitate clear and consistent communication, each child/family should have a key worker to coordinate supports and intervention.

Setting and staff ratios

There is no evidence to indicate one location as superior to others. Location of intervention should be tailored to suit each child and family's strengths and needs, taking into account the program requirements and the goals. Options for settings include the home, a centre, or a childcare or educational setting. These settings can be autism specific or include children with other developmental difficulties and/or typical children (mainstream). The evidence for peer programs from the age of 3 years suggests that programs should focus on transition to regular early childhood or educational settings to provide opportunities for interaction with typical peers (NAC, 2015; Wong et al., 2014; NICE guidelines, 2013).

Staff support, both number and their training, will also depend on the child and family's strengths and needs, their program plan and goals. Interventions that require 1:1 child to professional, more than one child with autism to one professional, small groups of children with autism and other developmental problems and/or typical children are all potentially appropriate, depending on the aims, approaches and actions in the support plan and learning and participation goals. Programs may also involve parents working with the child, or parents working with professionals. Implementation of individual child goals in a small group setting is likely to require a ratio of no fewer than 1 adult to 3 children.

The optimal location of early intervention for a child is likely to change over time and will be contingent on the degree to which the child is able to learn and participate in different settings. Key considerations include; working towards inclusion with typical peers in mainstream and community settings and independent participation, providing opportunities for interacting with peers who do not have autism, assisting transition to school and other settings, and maximising participation outcomes.

Professional development and training

Professionals should be trained to work with preschool children and in early intervention using family and child-centred approaches (see above section about family-centred approach), and have relevant and up-to-date training and experience in autism. Staff professional development, mentoring and coaching should be provided on a regular basis (for example, 2 workshops per annum with some ongoing coaching).

Parent training and development

Parent training and coaching are reported as an essential component of many evidence-based interventions, in particular those focusing on younger children (toddlers) with autism. Specifically a parent training package (NAC, 2015), parent-implemented intervention (Wong et al., 2014) and parent training in social communication (Weitlauf et al., 2014) have been supported as evidence based for children from birth (NAC, 2015).

Parent involvement potentially enhances learning opportunities and generalisation across home and community settings. The types of parent training that are supported by evidence 'aim to increase the understanding of, and sensitivity and responsiveness to, the child's communication and interaction' (NICE guidelines, 2013). As with other support and intervention planning, parent values, preferences and capacity are key to decision making about the appropriateness and timing of including parent training and coaching. However, not all interventions based on parent training have an established or emerging evidence base. Those without an evidence base should not be implemented.

In addition to training for both professionals and parents in the implementation of specific interventions, information and training for both parents and professionals is required to facilitate an understanding of:

- heterogeneity and variability of autism including understanding of the likely developmental unevenness of autism over time
- the interaction between characteristics of autism and the environment
- the importance of developmental age and stage and comparison to typical development
- the limitations of research.

Peer interventions

The provision of opportunities for engaging with typical peers is a common theme that is discussed in choice of setting and transition planning. Peer training package (NAC, 2015) and peer mediated instruction and interventions (Wong et al., 2014) are reported as evidence based. Structured play groups that include 'the specific selection of typically developing peers to be in the group' are also reported as an effective intervention (Wong et al., 2014). It is suggested that peer interventions are effective for children aged 3 and over (NAC, 2015).

Intervention programs

Program requirements

Intensity

In reviews and publications information about the usual intensity and duration of interventions was provided for comprehensive intervention programs (NAC, 2015). Also provided was information about child:professional ratios, including an expectation for 1:1 and small group sessions to be included (NAC, 2015). Little evidence was summarised about hours of intervention delivered by parents/carers, siblings or peers following training. More information is provided about intensity and child:professional ratios in the next section as a response to Q 2.

Quality

‘Quality of intervention is as important as quantity’ (Prior & Roberts, 2012).

Delivery

Ensure program or intervention is delivered with integrity. Interventions should have built-in fidelity measures. Manualisation increases confidence that programs are being implemented with fidelity. Staff and parent training (see above) which includes coaching and mentoring increases potential for an intervention program to be implemented with fidelity.

Evaluation

‘Evaluation of intervention outcomes should be built into early intervention programs using systematic assessment of the child’s social, cognitive and adaptive functioning before, during and at the end of the program.’ (Prior & Roberts, 2012). Once intervention is commenced ‘professionals have the responsibility to collect data to determine if an intervention is effective’ (NAC, 2015).

Program types

Comprehensive intervention programs

Three reviews identified evidence-based comprehensive interventions and of these 2 reported that intensive interventions that are based on applied behaviour analysis are effective for young children with autism (NAC, 2015; Weitlauf et al., 2014). In one report these interventions are referred to as Early Intensive Behavioral and Developmental Interventions (Weitlauf et al., 2014) and in the other as Comprehensive Behavioral Treatment for Young Children (NAC, 2015). Although a third review included evaluation of these types of programs they were not specifically included in the recommendations that were developed from that evidence review (NICE guidelines, 2013). The fourth review did not include programs for evaluation but directed the reader to an increasing number of ‘comprehensive treatment models’ that are characterised by ‘organization (i.e., around a conceptual framework), operationalization (i.e., procedures manualized), intensity (i.e., substantial number of hours per week), longevity (i.e., occur across 1 or more years), and breadth of outcome focus (i.e., multiple outcomes such as communication, behaviour, social competence targeted)’. Examples of the types of interventions considered as Early Intensive Behavioural and Developmental Interventions (Weitlauf et al., 2014) and Comprehensive Behavioural Treatment for Young Children (NAC, 2015) that have specific names are the Early Start Denver Model, Treatment and Education of Autistic Children with Communication Handicaps and University of California Los Angeles (Lovaas) Program. PRT is also an evidence-based, behavioural intervention, which incorporates naturalistic principles to increase child motivation in natural settings (NAC, 2015; Wong et al., 2014). It may also be referred to as a strategy (see section above) that is part of an individualised program (Weitlauf et al., 2014). Other programs that do not have a specific name but were referred to as ‘intensive behavioural intervention’ or ‘early intensive intervention’ were also included (Weitlauf et al., 2014). Play-based interventions were also reported to be effective especially for young children. ‘Results from a variety of play-based interventions also suggest that young children often display short-term improvements in early play, imitation, language, and social interaction skills’ (Weitlauf et al., 2014, p. 89). However, the strength of the evidence at this point in time is low, especially in relation to long-term effectiveness (Weitlauf et al., 2014).

Other considerations

Co-occurring or related conditions

Co-occurring conditions such as intellectual disability, learning disabilities, attention deficit hyperactivity disorder, conduct disorders and epilepsy, should be noted and managed accordingly with reference to evidence-based interventions for each condition. These conditions occur with sufficient frequency in children with autism that professionals should have knowledge about them and know to refer for further diagnostic assessment if they are suspected. Professionals should also be aware of how these conditions can impact planned early-life supports and intervention approaches.

Co-morbidities such as anxiety, post-traumatic stress disorder, and constipation, should be identified and treated appropriately. Ensure that any co-morbidities are known and managed. Differential diagnosis may be challenging when symptoms of a comorbid disorder are assumed to be characteristics of autism. For example obsessions and panic attacks may be labelled as behaviour problems synonymous with ASD rather than being considered as indicating a comorbid anxiety disorder.

Evidence-based interventions for co-morbidities should be considered with knowledge of the individual's autism characteristics. For example cognitive behaviour therapy, although an evidence-based intervention, will only be suitable for children who have sufficient language to understand and reflect on their experience.

Capacity building

Technical support, such as video conferencing, was suggested as a potentially useful way to extend the reach of an intervention and to build capacity. This is of particular relevance in the Australian context and for families living in regions which have low numbers of trained staff who are easily accessible in person.

Recommendations

1. these key elements be included in all support for young children with autism and their families
2. that programs offered to children and their families be assessed to ensure that they include these key elements
3. further work be undertaken to develop decision-making supports for families so they can take these key elements into account when choosing and prioritising interventions and support for their child and family.

Interventions that should not be used

Interventions that should not be used are shown in Table 4 (NICE guidelines 1.3.2 and 1.6).

Table 4 Interventions that should not be used for the problems listed

Problem to be addressed	Interventions that should not be used
Autism in any context	Secretin Chelation
Core features of autism	Exclusion diets (such as gluten-free or casein-free diets) Medications — antipsychotics, antidepressants, anticonvulsants Hyperbaric oxygen therapy
Speech and language	Neurofeedback Auditory integration training
Sleep	Omega-3 fatty acids

(from 1.3.2 and 1.6 Interventions for autism that should not be used, NICE guidelines, 2013)

In line with the recommendations from the NAC (2015) report (see evidence-based section above) interventions that are not yet evidence based or that evidence indicates are not effective and possibly harmful, should also not be used (Textbox 3).

Textbox 3 Interventions that are not evidence based as reported in the NAC review

Animal-assisted Therapy
Auditory Integration Training
Concept Mapping
DIR/Floor Time
Facilitated Communication
Gluten-free/Casein-free diet
Movement-based Intervention
SENSE Theatre Intervention
Sensory Intervention Package
Shock Therapy
Social Behavioural Learning Strategy
Social Cognition Intervention
Social Thinking Intervention

Question 2. Individualised levels of early intervention support

What characteristics or other factors would assist in deciding individualised levels of early childhood intervention support needed for a child with autism?

Characteristics of each child and family

Decisions about the level of intervention and support most likely to meet the needs of any one child with autism should take into account a range of characteristics of the child and family.

Characteristics of the child include the child's age and stage, the number and extent of the characteristics of autism identified in the child's diagnostic assessment (the severity of the child's autism), the presence or otherwise of intellectual disability or developmental delay and whether or not there are co-occurring mental health conditions or other conditions (for example, attention deficit hyperactivity disorder).

Characteristics of the family include the needs of a family because of the family structure (for example, whether there are siblings with additional needs), support available to the family and their ability to access resources (for example, is their location rural or remote) and the personal capacity and preference of parents.

The question of the influence of child characteristics on outcomes is not addressed in any detail in any of the reviews. The overarching emphasis in the reviews is that it is difficult to predict which children will respond well to intervention and an individual approach is recommended (NICE guidelines, 2013; Schreibman et al., 2015; Weitlauf et al., 2014; Wong et al., 2014). That said, the following was reported, although not in any detail:

1. Children with greater baseline cognitive skills and higher adaptive behaviour scores at baseline have better outcomes from early intensive applied behaviour analysis (ABA)-based interventions (AHRQ).
2. Younger children have better outcomes from early intensive ABA-based interventions (AHRQ).
3. For young children (aged less than 2) a potential modifier of treatment efficacy includes baseline levels of object interest (AHRQ).
4. Very young children may be particularly responsive to naturalistic behavioural interventions as these children are less likely to have established patterns of maladaptive behaviour (Schreibman et al., 2015).
5. Among these very young children, Schreibman et al. (2015) reported reduced dependence on prompts, more natural sounding language, habituation to real world distractions and improved adult-child social interactions resulting from naturalistic behavioural interventions.

These findings are not sufficient to form a basis for decisions about levels of intervention. To date there is little evidence that will allow individualised levels of early childhood intervention support to be decided based on specific child characteristics, especially at the time of entry to early intervention support. At the time of first seeking support because their child has been diagnosed with autism parents have not yet had an opportunity to develop sufficient understanding of the strengths and difficulties of their child or understanding of the way these characteristics may influence their choices about the available options for intervention and support.

Characteristics of support or early intervention programs

Duration and hours

Described in Q 1 are the many facets of early intervention support that are important for children with autism and their family, and that can vary between children and families, and for one child and family over time. Also mentioned above, and in more detail in response to Q 3, is the need for individualised planning to achieve best practice in providing early intervention supports.

Two characteristics of early intervention support that are directly linked to ‘level of support’ are intensity and duration. The requirement that early intervention and supports should be sufficiently intense, timely, and that a sustained program should be offered if a child continues to have additional needs, is frequently endorsed. Table 5 lists the recommendations about intensity and duration from the 5 reviews and publications on which this report is based. Intensity and duration were only mentioned in relation to comprehensive programs, as shown, and so were not relevant to the Wong et al. review (Wong et al., 2014). Comprehensive programs were included in the review of evidence that formed the basis of the NICE guidelines, but no guidance about intensity and duration were made (NICE guidelines, 2013).

Table 5 Intensity and duration of early intervention or supports from included publications

Review*	Program, intervention or support	Intensity	Duration	Professional: Child ratio
NAC	Comprehensive behaviours treatment for young children	25–40 hours per week	2–3 years	1:1 and small group
Wong et al.		No recommendation	No recommendation	Comprehensive programs not included in review
AHRQ	Early behavioural and developmental intervention based on the principles of ABA	>15 hours per week	Not included in recommendation	Not included in recommendation
NICE		No recommendation	No recommendation	No recommendation
Schreibman et al.		No recommendation	No recommendation	No recommendation

* Reviews are NAC = NAC, 2015; Wong et al. = Wong et al., 2014; AHRQ = Weitlauf et al., 2014; NICE = NICE guidelines, 2013; Schreibman et al. = Schreibman et al., 2015.

Other guidelines and systematic reviews identified by the initial search conducted for this report covered a wide range of intervention and support types and did not always discuss the intensity and duration of early intervention and supports (see Appendices 7–9).

Emerging evidence is in line with the recommendations made previously in Australia (Prior & Roberts, 2012) for between 15–25 hours of early intervention per week. Intervention should be available for at least 1 year, with review and changes to the level of support based on the recommendations made in response to Q 3. Support should be provided in encounters with professionals with training as described in Q 1 and delivered 1:1 or in small groups.

Other important factors that will influence decision making about level of support

Children are individuals, and each child will vary in comparison to other children with and without autism. Children will vary in their potential for learning at different time points. Put another way, the learning trajectory for individual children may rise, plateau or even fall at different stages of their development, and is likely to vary across developmental domains (for example, motor and communication) and even within one domain (for example, expressive and receptive language). For example an individual child may lag behind with language development but be advanced in gross motor abilities for their age or may plateau with language development and then make rapid gains.

The following factors should be taken into account when considering the level and type of support to be offered:

- the developmental age and stage of the child and their readiness for an intervention in relation to the approach and intensity of the intervention
- consideration of the zone of proximal development for a child, that is consideration of the child's current developmental level, in order to design an intervention to move them into the next stage of development
- response to intervention may be variable and is likely to be related to a child's autism characteristics.

As discussed in Q1 and also in Q3, assessment of child and family characteristics remains the essential first step in the intervention and should be informed by the considerations outlined above.

Level of support expressed as hours and duration does not address the following issues:

- what is the right level of training for the professionals/personnel providing early intervention support? Some information about this is available in Q1 but the recommended ratio of allied health professional time to other appropriately trained therapists/early intervention workers was not easy to distil from existing literature.
- the number of hours that should be spent in 1:1 versus small groups led by professionals
- intervention and support integrated into the child's daily routines, usually by parents.

Other considerations

Currently there is a high level of community awareness about autism. Alongside this, it is widely known that opportunities to change development and behaviour exist and that children of a young age have brains that are more 'neuroplastic' than older children and adults. This places parents and carers under considerable pressure to ensure their child is diagnosed if they have autism so they can receive the intervention they need as early as possible.

At the time their child is diagnosed, if they are the first in the family to receive a diagnosis, parents know the least they will ever know about autism, and their child's particular strengths and difficulties. They also know the least they will ever know about available services, their advantages and disadvantages and whether they are the right fit for them and their child.

If services only cater to children with disabilities who are likely to benefit the most from intervention there is reasonable cause for concern that children who do have potential will be missed because the science of identification is not yet precise. Questions could also be raised about whether such practices are ethical and equitable. We also know that parental adjustment to having a child with a disability is not a rapid or smooth process and that adverse experiences in the period following diagnosis can impact their ability to provide support for their child. It is also possible that early adverse experiences could negatively influence their ability to provide support for their child for future years.

Summary and recommendations

Autism is a highly heterogeneous condition and children and families vary significantly in their characteristics, strengths, needs and capacity. Support and intervention need to be tailored to individual children and families.

A decision about the level of early intervention support is a funding (or package) decision made prior to commencement of a support program being implemented. Even if, as is ideal, detailed information about an individual child's strengths and difficulties is available to those making this decision, there is not yet sufficient evidence upon which to base individualised decisions about the level of early intervention support for children with autism based on these characteristics.

Current best evidence to inform decisions about level of support is about intensity and duration of comprehensive interventions that have been shown to be effective. There are factors other than evidence that need to be taken into account when making decisions about level of intervention for young children, including ethical and equity considerations and long-term impact of the way parents adjust and adapt to their child's and their own individual needs.

We therefore recommend that children who have received a diagnosis of autism receive 20 hours per week of early intervention that involves interaction with them (focus on social communication), with review of this level of support after the first 12 months, or sooner if they fail to progress or make rapid progress. Review of progress should be more frequent (see Q 3) but review of the level of support is not needed more than 12 monthly unless otherwise indicated. In addition a package to support the child's family (for example, counselling or respite) be provided.

Assessment of children and families to determine the best type, intensity and duration of intervention is an essential first step in the individual planning process.

The level of support comes with requirements that:

1. the support for the child and family fulfils specifications provided in Q1
2. the support is sufficiently flexible that it can be adapted and modified in line with the child and parents' needs (see Q3).

Following an allocation of support at this level parents will still need support to choose the most appropriate type of intervention for their child, their situation and their preferences, and also to identify their family's support needs.

Whether this recommendation is feasible in Australia today is outside the scope of this report.

Question 3. Factors that indicate a need for a modification to an intervention program and timeframe for review of outcomes

What factors, including intervention outcomes would indicate a need for a modification, for example, an increase or decrease to intensity and/or type of intervention, once an early intervention program has been in place, and the recommended timeframe for review of outcomes?

Factors that could influence intensity or type of intervention

Review of the research reviews and available good practice guidelines identified only modest information about factors that could be used to guide modification to amount and type of intervention, summarised below (Textbox 4).

Textbox 4 Predictors of outcome: themes emerging from the key reviews or guidelines

Greater parent involvement was associated with greater gains in joint attention and parent child communication synchrony predicted better outcomes.

Parents experiencing high levels of stress benefited most from home based early intervention.

Children who responded well early in the intervention were found to make greater gains, i.e. most gains in first 6 months. However duration of treatment had an inconsistent effect.

Greater baseline cognitive skills and higher adaptive behaviour scores are associated with better outcomes, however this was not consistent for all reviews or guidelines.

Nonverbal cognitive ability was the most stable predictor of long-term outcomes

Those with lower symptom severity improved more compared to those with high symptom severity.

Social orienting in young children is a predictor of positive changes in ASD characteristics as measured on one diagnostic test. In young children, predominant object orientation predicted poorer social communication outcomes, those with more social orienting had better social communication outcomes. This was particularly the case for young children aged less than 2.

Severity of autism symptoms predicts gains as a result of intervention, which implies that children with more severe autism will make less progress over a longer period of time. 'Children with greater baseline cognitive skills and higher adaptive behaviour scores at baseline have better outcomes from early intensive ABA-based interventions' (AHRQ). However it is not yet certain what early changes from baseline measurements of child characteristics might predict long-term outcome and response. (AHRQ).

(**Bold text** indicates themes that appeared in more than one review or guideline)

There was consensus that an individualised approach is required because of the variability in response to intervention between individuals and in any one individual over time. Valid, reliable standardised measures may provide some useful information about change in individuals over the long term, however the recommended method to measure intervention outcomes for a child/family is individualised goal setting as part of a systematic, collaborative (support team, family and child with autism), and individual planning process. This is the most effective way to measure change and

to plan, implement and review intervention type and intensity for each individual.

Good practice in individual planning

There is insufficient evidence to allow individualised intervention planning based on a few key characteristics, in a way that would lead to predictable and consistent changes in outcomes for every child in a predictable time period. The heterogeneity of autism and variability in response to intervention highlights the need for detailed individualised planning to provide a mechanism for ensuring that decisions can be made about appropriate increases and decreases to intensity and changes in type of intervention as needed for individual children.

Some key good practice principles relevant to individual planning are shown in Table 6.

Table 6 Principles informing the individual planning process

	Recommended that the individual planning process:
Child centred and family focused	Involves focusing on the development of problem solving, cooperation, functional independence, and organisational abilities for children and incorporating family priorities and preferences.
Holistic	Is holistic (for the whole child) and includes a range of domains: social, communication, behaviour, joint attention, play, cognition, school readiness, motor, adaptive, mental health. For school-aged children, academic skills may also be relevant, for example, reading and numeracy skills.
Collaborative	Includes all of those in key relationships to the person with autism and as far as is possible the person with autism themselves.
Team Based	Incorporates input from relevant professionals and family members in all the relevant developmental and functioning domains: social, communication, behaviour, joint attention, play, cognition, school readiness (transition to school), motor, adaptive, mental health.
Strengths focused	Incorporates the abilities and interests of the person with autism.
Ecological	Accounts for available resources in the child and family's social and physical environment and considers the need for and implementation of, environmental modifications and management, and the provision of additional resources (for example, family respite, support for child to access local mainstream child care or preschool).
Change over time	Children and families' need for help and support will change over time. Clinicians should be prepared for a long-term collaboration and understand that for very young children issues of diagnosis and identification of treatment programs will be a priority. As the child progresses through early intervention and into school different priorities will emerge. Priorities and need for support may change over time as the child grows and develops.

The literature supports some key recommendations for the individual planning process (Table 7).

Table 7 Key recommendations and considerations for the individualised planning process

Key components	Recommendations from the research literature*
Assessment for program planning Individualised intervention plans must include a carefully designed assessment plan that includes baseline assessment and periodic follow-up assessments of any changes in core deficits. Baseline individual assessment of the child is essential to identify strengths and weaknesses across all areas of development.	Schreibman et al.: Individual planning including assessment of individual strengths and needs is associated with positive outcomes. Goals are typically developed with the use of standardised assessment, observation and developmental checklists, to help guide the clinician in choosing developmentally appropriate treatment goals across domains and teaching targets.
Goal setting Assessment informs the development of program goals for the child and family, which should be clearly defined and regularly reviewed. Individual goal identification and mechanisms for measuring whether these goals have been achieved is the optimal approach for making decisions about individual type and levels of early childhood intervention support for each child.	Wong et al. describe a process for designing what they call ‘technical eclectic/evidence-support programs’ based on Cox et al. (2013) and Odom et al. (2012). ‘Such a process begins with the precise identification of individual goals and their statement in an objective and measureable manner’.
Implementation (choice of program/strategy) Goals are developed then intervention and/or strategy chosen to implement to goals.	In this approach the goal and outcome then direct the type of support needed (Wong et al.).
Data collection Data collection underpins the capacity to monitor and measure the progress of the child and family during the intervention process; this is essential to demonstrate how much learning is taking place, and whether the intervention needs to be modified in some way to expand or accelerate learning or to change programs for non-responders.	Schreibman et al.: Effective practices must be systematically and objectively verified through data collected to track child progress. Data collection methods may include trial-by-trial recording of children’s response to each opportunity, interval recording of child progress during a session, probes of specific behaviours, and use of curriculum-based assessments to examine progress at specific time periods (for example, monthly or quarterly). The method of data collection should be linked to child goals and then used to adapt the intervention to the specific needs of the child and family.
Evaluation Intervention programs need to be evaluated regularly to ensure that they continue to meet the needs of the child. This process involves a review of the intervention plan goals, review of the child’s skills and needs to ensure that the program is relevant, with collaborative development of revised/new goals, as appropriate. Evaluation of individualised strategies can be achieved using strategies such as Goal Attainment Scaling. This should be implemented as part of program development and review.	Wong et al.: The most important evidence supporting an EBP at the individual student level is the progress the student makes when the EBP is implemented. This places great responsibility on the practitioner to implement the EBP with fidelity, collect data on student performance to evaluate the success of the EBP in meeting the student’s goal. (Wong et al. p. 33). Schreibman et al ‘The method of data collection should be linked to child goals and then used to adapt the intervention to the specific needs of the child and family.’ (p. 8)

Key components	Recommendations from the research literature*
Review and revision	<p>NAC: Programs should be reviewed and revised if goals have been met.</p> <p>A change should be made to an intervention program if it has been correctly implemented in the past and was not effective or had harmful side effects.</p> <p>A change should be made to an intervention program if the intervention is contraindicated based on other information (for example, the use of physical prompts for a child displaying self-injury when touched).</p>
<p>Individual variability At any age, development in children with autism is frequently uneven and may plateau or even regress for a period of time. 30% of children with autism between 12 and 24 months of age go through a period of regression, i.e. stasis or loss of social communication skills. In addition problem behaviours may develop which interfere with learning and goal attainment. These behaviours need to be specifically managed</p>	<p>NICE guidelines (1.1.7) recommend referring children and young people with autism to a regional or national autism service if there is a lack of response to the therapeutic interventions provided by the local autism team.</p>
<p>Behaviours that challenge Develop a plan with the child and their families or carers that has steps to address any factors that may provoke behaviours that challenge. The plan could include interventions for behavioural problems, support for families and carers, and daily living and environmental adjustments, i.e. assess and modify environmental factors that may be triggering and/or maintaining the behaviour.</p>	<p>NICE: If behaviour becomes challenging, reassess factors identified in the care plan and identify any new factors that could have resulted in the behaviour change.</p> <p>Interventions should include:</p> <ul style="list-style-type: none"> • clearly identified target behaviour, agreed desired change & a way to measure change over time • focus on outcomes linked to quality of life • consideration of environmental factors • clear intervention strategy appropriate for child • specified timeframe for review and consideration of modifications to the intervention if expected change does not occur • consistent application in all settings • agreement about the intervention by all involved in the child's care. <p>If behaviour remains challenging consult senior colleagues and undertake a multidisciplinary review.</p>
<p>Timing and frequency of planning</p>	<p>Prior & Roberts.: The initial individual planning process, including assessment and collaborative development of plans should be completed within the first 3 months of the child enrolling in a service.</p> <p>An individual plan should be developed at least annually and a review of the intervention plan goals, the child's skills and needs completed at least every 6 months to ensure that the program is relevant, with collaborative development of revised/new goals, as appropriate.</p>
<p>Coordination</p>	<p>NICE: A key worker/case manager should coordinate the IP process.</p>

* Reviews are NAC = NAC, 2015; Wong et al. = Wong et al., 2014; NICE = NICE guidelines, 2013; Schreibman et al. = Schreibman et al., 2015; Prior & Roberts = Prior & Roberts, 2012.

In summary for initial assessment for program development (Q2) and assessment for program outcomes review and revision (Q3) it is essential to include consideration of factors such as age and stage of child, provision of a program to meet the child's strengths and needs, degree to which autism specific intervention is indicated compared to generic early intervention, likely optimal intensity and duration, optimal location of program (for example, home based versus centre based), family capacity and preferences, resources such as availability of early intervention services/programs, evidence base for a program or strategy, quality of program and accountability.

Recommendations

In the NDIA planning occurs at two levels:

1. A plan developed by the NDIA planner. This individual plan will address long term goals for the child/family and describe in broad terms the intervention support needed and also address other needs, such as respite (see Q2) and provide the level of support.
2. A plan developed by each child's support program team. This individual plan directs the specific approaches and strategies used for support, and develops a framework for evaluating their success.

Individual planning by the NDIA planner

The planner will review the child/family plan every 12 months to assess the level and type of ongoing support required.

The planner will review the initial plan collaboratively with family and relevant professionals to assess the suitability of the intervention provided for the child and family with consideration given to factors outlined in Q1 and Q2. The detailed program review by the support program team (as outlined above) will inform the planner's review.

The planner's review should include review of child and family factors, changes, priorities, review of long term goals, resources, strengths and needs.

The planner will make recommendations about any changes required to the child's plan including level and broad types of support required for the next 12 month period.

Planners will require professional development to ensure they have the skills to evaluate the quality of the plan and the review.

Individual planning by the support program team

The service provider will coordinate the support program team and engage in a collaborative planning process within 3 months of enrolling a child. The planning process should involve all relevant people in the child's environment including parents (support team) and to the degree possible the child him/herself. The plan should be reviewed every 6 months and revised annually. The process should be team-based and involve practitioners with perspectives of health, education, communication and cognition as a minimum. In the Australian context there is an advantage in using consistent approaches — such as the Positive Partnerships planning matrix which embodies key elements endorsed as important by one or more of the included reports/reviews (available at

www.positivepartnerships.com.au/planning-matrix). The Positive Partnerships Planning Matrix was developed for school aged children, for very young children with autism change the domain heading *Learning Style/Information Processing to Development/Thinking and Learning* to include key development in areas such as toileting, motor skills, sleeping.

The planning process involves:

Analysis of learning strengths and needs

Assessment of child and family (see Q2). Some of this information will have been summarised by the planner. Detailed assessment of the child across all domains (see planning matrix for an example of this process). Assessment for program development should include the strengths of the individual which can potentially be utilised and extended. For example visual information processing skills can be developed to compensate for poor auditory comprehension.

Prioritising

Collaboratively prioritising areas to work on as identified in the assessment process, for example aspects of functional skill development (particularly social communication) and management of behaviours that challenge, are likely to be high priority.

Goal setting

Goal attainment scaling is potentially useful for developing and implementing, reviewing and revising program goals.

Development of an individual learning plan

Determination of intervention/program/strategies to achieve goals and resources required (including but not limited to funding).

Implementation of strategies/program

To achieve goal.

Evaluation

Regular monitoring of gains, losses, lack of change.

Review

Review by the program team will:

1. Allow timely modification of support based on changes — either improvements or new or persisting difficulties — in relation to the approaches and actions being used for early intervention, the location and the people involved.
2. Allow information sharing with those who allocate funding (packages) to ensure the appropriate level of funding is available for the child and family
3. Demonstrate early intervention supports are being offered in a way that is consistent with good practice.

Recommendations for best practice and research

All evidence summaries and guidelines have made recommendations for future research, identifying that we need to know more to both increase the strength of evidence in relation to current findings and to continue to improve the supports we are providing to children with autism and their families.

The research recommendations made by all the overseas based reviews, reports and guidelines included in this report are grouped and summarised in Appendix 10. As NDIA implements national provision of early support services for children with autism in Australia it is timely to consider how the NDIA and those who deliver services funded by them could contribute to this internationally relevant research agenda. Are there, for example, strategies that could be incorporated into early intervention that would provide the type of data needed to answer more than one of the questions posed? Which of these strategies would be necessary for ensuring best practice and what may need to be added for a research framework?

We propose that to achieve best practice and to advance knowledge all children have:

1. an individual plan for each child is created based on the matrix provided in Q3
2. the individual plan includes goals and a method to assess whether each goal has been achieved – outcome measure
3. that whether a parent was involved in developing the individual plan, including outcomes, is documented
4. the individual plan includes the type(s) of intervention being used
5. that individual plan be reviewed at least every 6 months, or sooner if great gains are made, difficulties increase or new difficulties are identified
6. that outcomes be measured at least every 6 months to assess goals
7. that a functional assessment, assessment of adaptive behaviours and also an assessment of social communication be completed at least every year – as indicators of progress in key areas addressed by early intervention
8. that early intervention services provide the names, qualifications and experience of their early intervention professionals to NDIA
9. that NDIA is notified as to whether a key worker was assigned to a child and who they are, if one was assigned
10. that early intervention professionals keep a record of their early intervention encounters with each child, including information about:
 - a. number of face-to-face hours per week
 - b. whether the encounter was 1:1 or group based, and if group based the ratio of professionals to children
 - c. the setting in which the intervention occurred
 - d. whether a parent/carer or child care worker was being trained
11. that information is gathered from parents/carers about their experience of the interventions offered
12. that information is sought from parents of children with autism to understand their preference for and experience of parent engagement in early interventions offered
13. that information is collected about parent/carer health and wellbeing.

Planning for use of agreed mechanisms for monitoring outcomes over time is also needed.

Appendix 1 Stakeholder group meetings

Date	Purpose of meeting
November 17, 2014	Stakeholders invited to participate in the project. All stakeholders who were invited accepted and signed a Confidentiality Agreement and Terms of Reference. Selection of the stakeholder group aimed to include key people who would offer expertise and/or lived experience relating to early intervention for autism. The group also aimed to include people from different personal or professional backgrounds, living in a range of locations across Australia.
December 2, 2014	Meeting to introduce the project, scope and discuss commitment and involvement in the project. The draft project brief was tabled at this meeting and feedback was sought with regards to the wording and content.
December 18, 2014	Meeting to discuss feedback obtained regarding the project brief. Project brief was finalised.
April 23, 2015	Meeting to discuss interim report. An interim report was sent to the stakeholder group prior to this meeting. Each attendee briefly presented their feedback on the interim report and then emailed written comments. This information was forwarded to the research consultants for consideration.

Appendix 2 Project outline

Section A – Project questions and overview

Section B – Definitions and timeline

Section C – Methods

Section A – Project questions and overview

Project Questions

The National Disability Insurance Agency (NDIA) seeks to answer 3 questions:

1. What is evidence-based/evidence-informed good practice for supports provided to children with autism and their families/usual carers - with a focus on the autism specific elements?
2. What characteristics or other factors would assist in deciding individualised levels of early childhood intervention support needed for a child with autism?
3. What factors, including intervention outcomes would indicate a need for a modification, for example, an increase or decrease to intensity and/or type of intervention, once an early intervention program has been in place, and the recommended timeframe for review of outcomes?

Context and considerations

The NDIS aims to provide funding of early childhood supports for children with autism within a good practice framework and in a cost-effective manner, supporting the choice of well-informed families and/or carers. Funded supports aim to achieve relevant outcomes for children and their families, and should be seen in the context of potential outcomes, rather than only in terms of 'hours' or a specific type of intervention. The NDIA is not seeking to identify specific interventions, nor to rate interventions against each other, this project will provide guidance towards sound decision making. While some areas are identified as being 'out of scope', we realise there will be grey areas and information that is beyond the scope of the existing project will be identified for future possible work. The current project is not specifically a study of outcomes, nor is it a comprehensive study of interventions for autism; it is intended to inform practice within the context of the NDIS.

The proposed method allows for input from as broad a range of people as possible during the timeframe of the project. The stakeholder group will be kept informed of the process and invited to advise in response to progress reports and at other times, as relevant. In addition to the stakeholder group, a wider consultative group will include parents, researchers, practitioners and representatives of peak and local organisations. Steps will be taken to ensure the process is manageable in terms of number of requests and easy submission of information.

Important issues that are out of scope for this project

A number of questions and issues were raised by members of the stakeholder group that are outside the project brief set by NDIA executive team. Many of these issues are key to ensuring good outcomes for children, however are not within the scope of this project. They may be considered for future projects and a number of the issues are already being addressed by NDIA.

- Specific lists relating to the relative effectiveness of programs are not within the scope of this project. This would be considered as an additional project to help participants decide between different types of therapy/programs, however is not a part of the current brief from NDIA executive.
- Evidence base underpinning outcomes for families and usual carers: families and usual carers are clearly an integral part of any early intervention plan; however this project primarily focuses on outcomes for children with autism.
- Development, readiness and quality of the workforce to deliver good practice: another important issue to be addressed within broader workforce development, and possible future work specific to autism.

Section B – Definitions and timeline

Definitions and terms used

Early childhood intervention is the provision of specialised supports and services to children with developmental delays or disabilities, their families and usual carers. This may include assisting learning, communication, social development, behaviour, physical skills and mobility, from any time from birth to school entry, in order to promote development, well-being and community participation.

In this document the word autism will be used for all autism spectrum disorders.

Relevant information

The severity and types of developmental problems that will be required for entry to NDIA early childhood intervention services are being developed during the trial period.

NDIA has commissioned Early Childhood Intervention Australia (ECIA) (further information about ECIA available at <http://www.ecia.org.au/>) to develop good practice recommendations that would apply to all children, to which specific recommendations focused on different types of developmental problems can be added.

Overall process and time frames

The NDIA has approached Professors Jacqueline Roberts and Katrina Williams to act as expert consultants (from hereon called the consultants) to oversee the gathering of evidence that will answer questions 1-3 above, and to produce a report of their findings.

Phase 1 development of the process for answering the questions

- NDIA to form a stakeholder group with broad representation from the autism community
- The consultants to present an approach to answer the questions as set
- The stakeholder group to provide input to the approach developed at their first meeting
- The consultants to review the approach, taking stakeholder feedback in to account, before commencing work

Phase 2

- Within 8 weeks of commencement of the project the consultants produce an interim report for the stakeholder group
- The stakeholder group to provide feedback about the progress of the work and suggestions about the methods and findings

- The consultants to modify their approach and review their findings taking stakeholder feedback into account

Phase 3

- Within 6 weeks of receipt of feedback from the stakeholder group the consultants present a draft final report
- Feedback is provided in a timely fashion and taken into account for the final report

Phase 4

- Within 2 weeks of receipt of feedback the final report is presented to the stakeholder group and the NDIA

Timetable

Jan 2015	Review stakeholder feedback
Feb	Start Project 9 Feb
March	Data searching and analysis
April	Interim report to stakeholder group 9 April Stakeholder feedback by 24 April
May	Further analysis, preparation of recommendations/issues
June	Final report for consideration due 8 June Stakeholder feedback 19 June Final report June 30

Section C – Methods for answering the research questions

1. What is evidence-based/evidence-informed good practice for supports provided to children with autism and their families/usual carers - with a focus on the autism specific elements?

Early Intervention for Children with Autism Spectrum Disorders: 'Guidelines for Good Practice' by Prior and Roberts was published in 2012

(https://www.dss.gov.au/sites/default/files/documents/11_2012/early_intervention_practice_guidlines.pdf). Since then there have been detailed reviews to identify intervention programs and components that have been proven to be effective.

To answer these questions the consultants propose 3 steps:

Step 1 (Q1)

- review evidence from systematic reviews that have been published since 2012 that provide information about key elements associated with effective early intervention programs. Key elements could include the types of problems that are addressed, the types of strategies that should be used, important issues about intervention setting and the types of professional skills involved.
- compare the key elements identified in these systematic reviews to the published guidelines by Prior and Roberts
- identify any points of difference by noting things that are missing from the published guidelines and things that are included that do not emerge from the evidence

Step 1 will focus on the key elements of effective early childhood intervention for autism, rather than the overall effectiveness of programs that have included key elements. The comparative

effectiveness of differently named early childhood intervention programs for autism will not be reviewed.

Step 2 (Q1)

Search the academic literature and websites (autism-related, government and non-government) for descriptions of key elements of good practice for early childhood intervention programs for autism and also review the evidence used to inform these.

Step 3 (Q1)

A wider group of people with expertise (the consultative group) in the field of early intervention for autism will be asked for their opinions of key elements for early intervention programs/approaches for autism. The stakeholder group will be consulted regarding the range of people to be invited, as well as any specific individuals. The consultative group will be contacted by email and an online survey provided for feedback. The survey will list key elements identified in the 2012 good practice guidelines and ask for a rating of the relevance of the identified elements from 'not at all necessary' to 'must be included' (or similar scale). The consultative group will also be asked to list any other elements that they feel should definitely be or definitely not be included.

Outcome (Q1)

The detailed methods of the proposed 3 steps and the findings will be reported. A summary of the key elements for early childhood intervention for autism will be proposed based on those findings.

Question 2. What characteristics or other factors would assist in deciding individualised levels of early childhood intervention support needed for a child with autism?

The consultants acknowledge that there are many factors to be taken in to account when deciding individual levels of early childhood intervention support. Step 1, while important, is not the only factor that should be taken in to account for each child.

The consultants are also aware that there is likely to be incomplete evidence specific to Step 1, and so have developed Steps 2 and 3 to identify factors and existing processes of importance.

Step 1 (Q2)

- review systematic reviews published since 2012 to identify if specific child or parent characteristics are known to be associated with differences in effectiveness of early childhood interventions, for child or parent/carer outcomes

Step 2 (Q2)

- search published evidence for information about approaches to making decisions about individual level of early childhood intervention for children with autism, to identify if specific characteristics have been identified
- search websites (autism-related, government and non-government) for information about approaches to making decisions about individual level of early childhood intervention for children with autism, to identify if specific characteristics have been identified.

Step 3 (Q2)

A wider group of people with expertise (the consultative group) in the field of early intervention for autism will be asked for their opinions of key elements for early intervention programs/approaches for autism. The stakeholder group will be consulted regarding the range of people to be invited, as well as any specific individuals. The consultative group will be contacted by email and an online survey provided for feedback. The survey will list factors that have emerged from Steps 1 and 2 and ask them to rank them as "not at all important" to very important" (or similar scale). The

consultative group will also be asked to list any other elements that they think are helpful and to describe how decisions about intervention level are made in the services that they have worked with.

3. What factors, including intervention outcomes would indicate a need for a modification, for example, an increase or decrease to intensity and/or type of intervention, once an early intervention program has been in place, and the recommended timeframe for review of outcomes?

The consultants will use a framework similar to individual planning and review of progress matrices as the framework for this question. As in Q 2 there is unlikely to be evidence that directly answers this question so the approach below has been developed.

Step 1 (Q3)

Review relevance of information gathered in response to Q 2, as it is likely that similar information for decision making about type and level of early intervention will apply. Identify possible differences in characteristics, such as response to intervention that will be available.

Step 2 (Q3)

- Review findings from reports and publications about outcome measures for autism
- Distil from these reports outcome measures that:
 - are reliable and valid
 - have relevance for parents of children with autism
 - have relevance for professionals
 - are suitable for use in an early childhood intervention setting
- Distil from these reports the most appropriate timing for review

Step 3 (Q3)

Present findings from Step 1 and 2 to the broader national and international consultative group to gather their perspectives about key elements of decision making about changes to level and type of early intervention for individual children.

Appendix 3 Interim report to stakeholders

Two consultants (Katrina Williams and Jaqueline Roberts) were involved in the production of the interim report.

Criteria for considering records for this review

To be included in this review, records needed to:

- Be either (a) a systematic review, or (b) an evidence-based guideline. Comprehensive literature reviews were also included if the article was highly relevant to the project questions. Systematic reviews that included all types of studies (single case and/or group designs) were considered.
- Include children from birth to 8 years of age. In cases where records included participants from a wider age range, the record was included if 50% or more of the participants were under 8 years old.
- Include children with a diagnosis of ASD, or any of the diagnostic classification category that is included under the broad heading pervasive developmental disorder (PDD) in ICD-10 or versions of DSM-IV or earlier versions, such as Autistic Disorder, Childhood Autism, Asperger syndrome or disorder and PDD Not Otherwise Specified (NOS). In cases where systematic reviews involved children with other diagnoses, the record was included if 50% or more of the participants had ASD or PDD/PDD-NOS.
- Contain information that would assist in answering at least one of the project questions.

Records relating to the following topic areas were not included in this review.

- Medical procedures
- Medication/drug trials
- Dietary interventions
- Genetic studies, pre/post natal studies
- Diagnosis and screening of autism
- Animal studies
- Complementary/alternative treatments

Search methods for identification of studies

The nature of the project questions led the authors of this review to perform both broad database searches as well as searching for records from a wide array of other information sources. Search terms were adapted for each database or other information source. Appendices *and * detail the search strategies used.

Electronic database searches

We searched the following databases for English language records published between 1 January 2011 and 18 February 2015.

- Ovid MEDLINE
- ERIC (Educational Resources Information Centre)
- CINAHL (Cumulative Index to Nursing and Allied Health Literature). The CINAHL search included the Cochrane Database of Systematic Reviews, part of The Cochrane Library
- PubMed
- speechBITE
- OT seeker
- PEDro
- PsycINFO.

As this was an update of the Prior, Roberts, Williams, Rodger and Sutherland (2011) review, searches were limited to the period 2011–February 2015.

Searching other resources

The following information sources were examined for systematic reviews or guidelines.

- Google Scholar citations were searched for each included article to identify records that were not yet indexed in the databases listed above.
- Bibliographies of key records for citations were examined to search for records not published electronically.
- Online databases of journals that regularly publish articles relevant to early intervention autism were searched (2011–February 2015).
- Websites and other databases were searched. See Appendices 2 and 3 for details.

Data collection and analysis

Selection of studies

Search terms were selected and adapted for each database after consultation between 2 review authors (LC and KS). LC and KS performed the searches on each database independently. All citations generated through the database searching process were imported into Endnote X7. Records were then independently screened by the same 2 reviewers for inclusion by title and where available, abstract. The full text was retrieved for any records with insufficient information in the title or abstract to decide whether it should be included or not. The same reviewers then compared included records and any discrepancies between included records were discussed and inclusion/exclusion criteria re-examined. This process resulted in 100% agreement between the 2 reviewers.

Data extraction and management

The full text versions of all included records were retrieved. Two evidence tables were created — one for systematic review literature and the other for guidelines.

Systematic review synthesis

LC and KS extracted and recorded the information in Table 8 from each systematic review. Where possible, data about children under 8 years of age were separated out from the larger data set.

Table 8 Information from each systematic review

Information categories	Data extracted
Participants	Total number of participants included in the systematic review Diagnosis/diagnoses, severity level, any other pertinent information Age
Included studies	Total number of studies included in the systematic review Type of studies included (e.g. randomised controlled trial)
Intervention	Type of interventions included (e.g. social skills training) Intensity, duration, follow up period
Outcomes	Details of the outcomes included
Results	Summary of results from the review Where possible, effect sizes were extracted and recorded
Project questions	Information the related to questions 1,2 or 3 of the project questions was summarised and recorded
Quality of included studies	Grading (where available) or comment regarding the quality and strength of evidence of the studies included in the systematic review

Guideline synthesis

LC and KS extracted and recorded the following information from each guideline:

- Source — authors, funding, organisation
- Background — what prompted the development of the guideline
- Ages covered by the guideline
- Methodology underpinning the creation of the guideline
- Summary of recommendations
- Project questions — information/answers to the 3 project questions.

LC and KS read each article in full, extracting information that was potentially relevant to each project question.

Results of searches

Multiple database searches retrieved 591 possible records for inclusion. There were 235 duplicates removed, with 356 potential records for the review. Screening by title or abstract resulted in 252 records being excluded. There were 104 records retained and the full text was retrieved for each of these records. A further 79 records were excluded when the full text was examined, with 25 records included in the final set from database searches. There were an additional 7 relevant records found by searching other information sources. Six of these records were guidelines and 1 record was a comprehensive overview of behaviourally based interventions for autism and all were found on websites Figure 1 is a flow chart showing the search and synthesis described above.

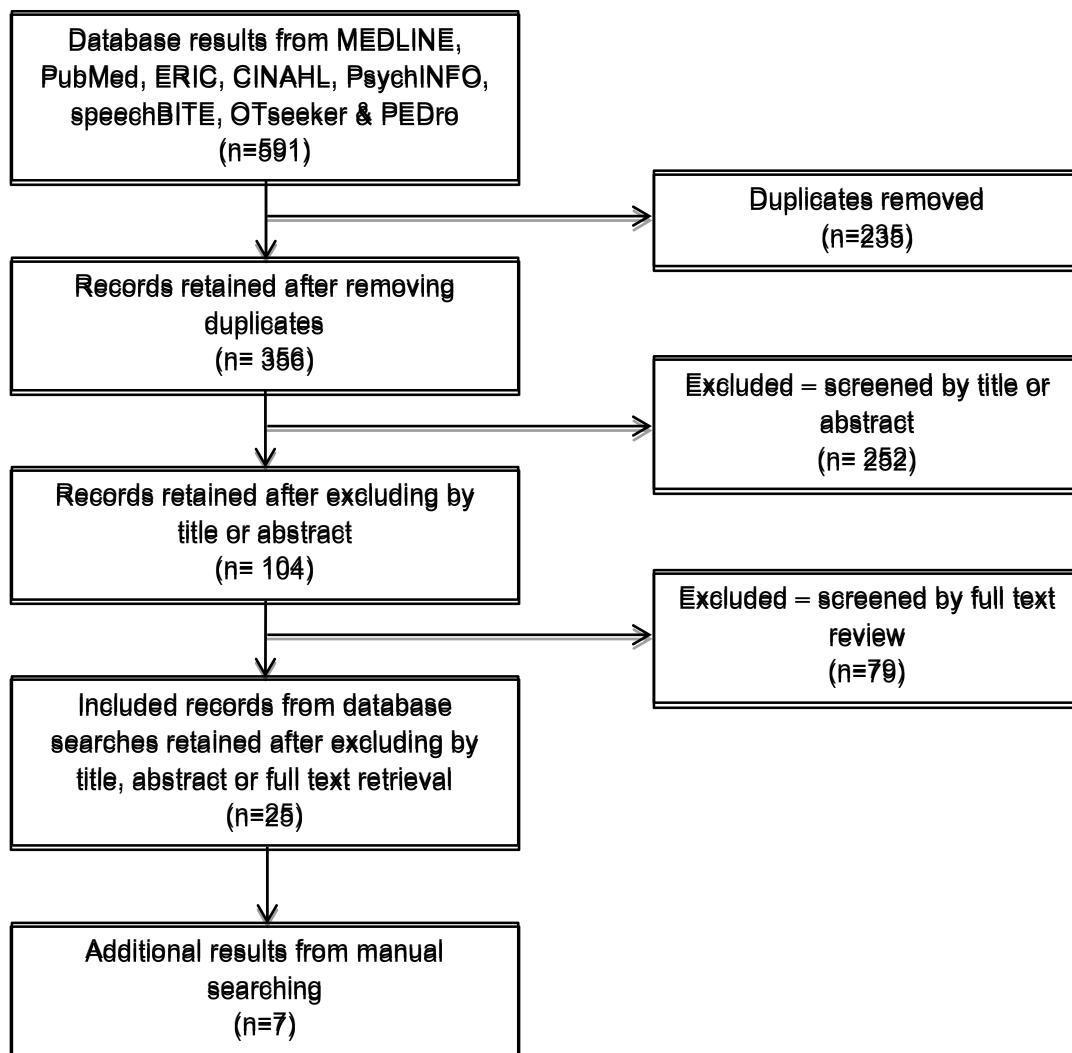


Figure 1 Selection of studies flow diagram

Extraction of key elements

Question 1

One consultant (MP) reviewed information extracted from all the papers/resources found and compiled a list of dominant themes for evidence-based/evidence-informed good practice for supports for children with autism and their families/usual carers—with a focus on the autism-specific elements. Those dominant themes were then cross-referenced against the NICE guidelines (2013) and the Weitlauf et al. (2014) by 1 consultant (KW) to identify if there were dominant themes that emerged from all the evidence gathered that were not addressed in the NICE guidelines (2013) or Weitlauf et al. (2014). Another consultant (JR) also assessed the relevance of emerging themes to early intervention.

A final list of key elements, with reference to the source, was then compiled. Consensus amongst all 2 consultants about the relevance of all the key elements included was achieved.

Questions 2 and 3

Two consultants (MP & JR) reviewed all the information extracted from all the papers/resources found and identified relevant findings. The AHRQ report was reviewed and relevant information extracted by 2 consultants (KW & JR). The 2 sources were combined for both Q2 and Q3 by 1 consultant (JR). Little evidence available relevant to these 2 questions was found and the 2 consultants reached consensus about the need to develop an approach that would provide guidance in an evidence-poor environment.

Key elements

Professional and care process elements

1. Professionals need to receive appropriate training to have 'autism awareness and skills in managing autism'. The specific components of this training are listed below.

- the nature and course of autism
- the nature and course of behaviour that challenges in children and young people with autism
- recognition of common coexisting conditions, including:
 - mental health problems such as anxiety and depression
 - physical health problems such as epilepsy
 - sleep problems
 - other neurodevelopmental conditions such as attention deficit hyperactivity disorder (ADHD)
- the importance of key transition points, such as changing schools or health or social care services
- the child or young person's experience of autism and its impact on them
- the impact of autism on the family (including siblings) or carers
- the impact of the social and physical environment on the child or young person
- how to assess risk (including self-harm, harm to others, self-neglect, breakdown of family or residential support, exploitation or abuse by others) and develop a risk management plan
- the changing needs that arise with puberty (including the child or young person's understanding of intimate relationships and related problems that may occur, for example, misunderstanding the behaviour of others)
- how to provide individualised care and support and ensure a consistent approach is used across all settings
- skills for communicating with a child or young person with autism.

(taken from Knowledge and competence of health and social care professionals, 1.1.8 <https://www.nice.org.uk/guidance/cg170/chapter/1-recommendations#families-and-carers-2>). Clearly the age and stage of the individual with autism will determine the relative focus of the training and expertise of those working with the individual and their family, however it is important that staff working with individuals with autism at all stages including early intervention have an understanding that this is a life long condition.

2. Local early intervention teams should produce local protocols to ensure shared care with education and health (adapted from 1.1.6 bullet point 10, second sub-point <https://www.nice.org.uk/guidance/cg170/chapter/1-recommendations#families-and-carers-2>)

3. Services should be culturally appropriate and consider family values as described in the section called 'Diversity, equality and language' of the NICE guidelines (2013) autism standard. Key points include 'Treatment, care and support, and the information given about it, should be

- a. both age-appropriate and culturally appropriate
- b. accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.

People with autism, and their families or carers (if appropriate), should have access to an interpreter or advocate if needed.'

(<https://www.nice.org.uk/guidance/qs51/chapter/diversity-equality-and-language>).

Involvement of parents and families

1. Involvement in decision making

"Provide children and young people with autism, and their families and carers, with information about autism and its management and the support available on an ongoing basis, suitable for the child or young person's needs and developmental level. This may include:

- contact details for local and national organisations that can provide:
- support and an opportunity to meet other people, including families or carers, with experience of autism
- information on courses about autism
- advice on welfare benefits, rights and entitlements
- information about educational and social support and leisure activities
- information about services and treatments available
- information to help prepare for the future, for example, transition to " primary school.

"Explore with children and young people with autism, and their families and carers, whether they want to be involved in shared decision-making and continue to explore these issues at regular intervals. If children and young people express interest, offer a collaborative approach to treatment and care that takes their preferences into account."

(extract from <https://www.nice.org.uk/guidance/cg170/chapter/1-recommendations#families-and-carers-2>, items 1.1.11 & 1.1.13)

2. Provide support for families (including siblings) and carers by providing information that takes into account their preferences, about how to access:

- a. respite care and child care
- b. an assessment of their own physical and mental health needs
- c. personal, social and emotional support
- d. practical support in their caring role, including emergency plans

(adapted from 1.2 <https://www.nice.org.uk/guidance/cg170/chapter/1-recommendations#families-and-carers-2>)

3. Parents and others are agents for intervention: 'aim to increase the parents', carers', teachers' or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction' (Psychosocial interventions 1.3.1 <https://www.nice.org.uk/guidance/cg170/chapter/1-recommendations#specific-interventions-for-the-core-features-of-autism>)

Appendix 4 Summary table with distilled principles

Section	Topic	Extracts from reviews*
Underpinning principles	Evidence base	<p>NAC: evidence-established interventions (a) have produced beneficial effects for individuals involved in the research studies published in the scientific literature,(b) expected to produce more positive long-term outcomes (c) no evidence of harmful effects.</p> <p>NAC: Given the limited research support for Emerging Interventions, these should not be used as first-line interventions. However, Emerging Interventions should be considered promising and warrant serious consideration if Established Interventions are deemed inappropriate by the decision-making team, or were unsuccessful in producing positive outcomes.</p> <p>NAC: Unestablished Interventions should only be used after additional research has been conducted and this research reveals favourable outcomes for individuals with ASD.</p> <p>NAC: A change to early intervention programs should be made if evidence from well-controlled studies is available but was too recent to have been included in existing guidance.</p>
	Families require support	<p>NICE Offer all families, including siblings, and carers verbal and written information about short breaks, respite and opportunities for assessment of their own needs. Make arrangements to support children and their families and carers at times of increased need.</p> <p>NICE When needs of families and carers are identified, offer assistance that takes into account their preferences especially if: they need help with personal, social or emotional care of the child and/or they are involved in delivery of an intervention.</p> <p>Prior & Roberts Support for family members via partnership with professionals involved in treatments should be included. Effective programs are sensitive to the stresses encountered by families of children with autism, and provide parent groups and other types of emotional support. Families are often in need of respite care, hence reliable provision for this service is essential to decrease family burden and stress.</p>

Section	Topic	Extracts from reviews*
	Family-centred	<p>NICE Provide children and their families and carers with information about autism and its management suitable to their needs and developmental level including: contact details of local and national organisations, information about services and interventions, information to help prepare for the future.</p> <p>NAC Before deciding on the early intervention program to implement it is important to consider: do the parents have capacity to implement the intervention based on what you know about their available time, money, and current experience and stress?</p> <p>Consider the values and preferences of parents, care providers, and the individual with ASD when an intervention is contrary to the values of family members.</p> <p>Consider the values and preferences of parents, care providers, and the individual with ASD when the individual with ASD indicates that he or she does not want a specific intervention.</p> <p>Consider the values and preferences of parents, care providers, and the individual with ASD when an intervention has been correctly implemented in the past and was not effective or had undesirable side effects.</p> <p>Prior & Roberts Families should be meaningfully involved in assessment, and in program development and implementation.</p> <p>NICE Explore with children and their families and carers whether they want to be involved in shared decision-making and adjust approach accordingly. Offer assessment for families, including siblings, and carers and assessment of their own needs</p>

Section	Topic	Extracts from reviews*
	Individualised Planning	<p>Prior & Roberts Need to account for the spectrum of autism disorder, no one child with autism will have the same pattern of strengths and needs as another. The need for support varies according to age and stage. An individual plan documents each child's strengths and needs and goals for intervention, and information about how these goals will be achieved and monitored. Every child receiving intervention should have an individual plan developed by all those involved, including family, early intervention providers, preschools or childcare services.</p> <p>Assessment of individual child strengths and needs in all relevant areas (e.g. communication, cognitive development) should guide intervention content and provide information about the best techniques for an individual child. The process should not be confused with assessment for diagnosis of autism.</p> <p>The individual planning should also take account of family goals, strengths, and needs.</p> <p>An individual plan documents each child's strengths and needs and goals for intervention, and information about how these goals will be achieved and monitored. Every child receiving intervention should have an individual plan developed by all those involved, including family, early intervention providers, preschools or childcare services.</p> <p>Schreibman et al. developmentally-based strategies and developmental sequences should be used to guide goal development that is individualised to each child.</p> <p>Effective practices must be systematically and objectively verified through data collected in order to track child progress.</p> <p>Prior & Roberts No one program will suit all children with autism and their families. There are benefits from early, intensive, family-based treatment programs, so long as these are adapted to the child's pattern of strengths and weaknesses and take account of family circumstances.</p>
Aims	Improve social communication	<p>NICE Consider a specific social-communication intervention to increase joint attention, engagement and reciprocal communication</p> <p>Schreibman et al. Address core issues such as engagement and joint attention while systematically improving specific communication, cognitive and other skills.</p> <p>Prior & Roberts Autism specific curriculum content focusing on attention, compliance, imitation, language, and social skills is needed .</p> <p>Prior & Roberts There are 5 basic skill domains that should be included in all interventions: ability to attend to elements of the environment; ability to imitate others; ability to comprehend and use language or alternative communication; ability to play appropriately with toys; and ability to engage socially with others.</p>

Section	Topic	Extracts from reviews*
Approaches	Minimise behaviours that challenge	<p>Prior & Roberts Focus on the prevention of problem behaviour by increasing interest and motivation, structuring the environment, and increasing positive behaviour support including teaching alternative appropriate skills, and communication strategies to replace problem behaviours. If problem behaviour persists, use functional behaviour analysis to determine its triggers, function, and consequences, and adapt environment to avoid triggers and to reinforce appropriate and adaptive behaviour.</p> <p>NICE Ensure there is no mental health, behavioural, environmental or physical problem triggering or maintaining the behaviour that challenges before offering a psychosocial* intervention.</p>
	Enhance learning and participation	<p>NICE Offer children support in developing practical coping skills for day-to-day living</p> <p>Prior & Roberts Promotion of independent functioning throughout the intervention programs</p>
	Environmental Management	<p>Prior & Roberts Highly supportive teaching environments which deal with the need for predictability and routine, and with challenging behaviours, obsessions, and ritual behaviours</p> <p>Core skills are taught in a highly supportive teaching environment and then systematically generalised to more complex, natural environments and to a wider range of people. Utilisation of appropriate environmental supports, structured teaching, and visual supports to assist with learning and generalisation.</p> <p>NICE Environment & content – Take into account the physical environment to minimise any negative impacts by: providing visual supports, making adjustments to the amount of personal space given considering sensory sensitivities</p> <p>Schreibman et al. Environment & content. A child's environment should be set up so that the child must initiate or interact with the adult in order to obtain a desired outcome, such as access to preferred materials or participation in preferred routine.</p> <p>Prior & Roberts Routines are established within and between sessions which are supported visually where appropriate and extended into family and other settings. inclusion of typically developing peers.</p>
	Building on opportunities	<p>AHRQ recommends play/interaction based approaches for young children with ASD.</p> <p>Schreibman et al. Promote shared control between child and therapist, use naturally occurring contingencies, natural reinforcement, (generally paired with social attention) intrinsic to the child's goal rather than unrelated to the child's goal, is ideal.</p> <p>Follow the child's lead, interest, or choice, present a teaching opportunity within that activity to increase the child's motivation for participation and to use the child's achievement of his or her goal as the positive consequence.</p> <p>Prior & Roberts Incorporation of obsessions and rituals into programs to engage the child and reinforce responses.</p>

Section	Topic	Extracts from reviews*
	Antecedent – behaviours – consequence	<p>Schreibman et al. All interventions should ‘utilize a 3-part contingency (antecedent-response-consequence) to help the child understand when to respond and to provide feedback to the child. However, the emphasis on contingency components may vary across interventions. For example, some interventions provide a clear antecedent in order to gain a specific child response, while other interventions prioritize environmental arrangement to facilitate initiation and responding behaviors from the child. Some interventions clearly specify contingent reinforcement as a component while others use the strategy without specifying it in behavioral terms.’</p> <p>NICE Develop strategies to address triggers or factors that could maintain behaviour that challenges including interventions for identified problems and adaptations to the physical environment or daily living.</p> <p>Routinely assess factors that may increase behaviours that challenge like communication difficulties, avoidable unpredictability, physical problems, the physical and social environment, changes to circumstances and routines, and possible abuse.</p> <p>Take into account the nature, severity and impact of the behaviour, the child’s communication needs, the environment, preferences of the child and their family or carers, prior experience and response to interventions and necessary supports or training for the family or carers when choosing an intervention.</p> <p>Assess factors that trigger the behaviour, the pattern of behaviour, the need of the child that is being met by the behaviour and the consequences of the behaviour.</p>
	Transition	<p>Prior & Roberts Support for children in their transition from the preschool classroom is needed.</p> <p>There should be systematic connection and integration between the early intervention program and the next stage for the child, whether it is transition to school or to another therapeutic or special educational setting.</p> <p>Transition supports for children with autism can include: assisting the child to learn appropriate skills (e.g. school readiness); collaboration and communication with new settings (e.g. schools) about the child’s current skills and needs; and actively supporting transition to a new environment through visits, visual supports and stories where appropriate. Parents, teachers and therapists need to collaborate in preparing the child for transition.</p>

Section	Topic	Extracts from reviews*
Action		<p>Prior & Roberts Provision of augmentative and alternative communication (AAC) for expressive and receptive communication.</p> <p>NICE Consider a specific social-communication intervention that includes play-based strategies with their parents, carers and professionals that include techniques of therapist modelling and video-interaction feedback.</p> <p>Schreibman et al. Vary from requiring the child to initiate an interaction (make a communication bid) to presenting a stimulus to gain child approach behaviour or child attention, and then prompting the child for a target skill.</p> <p>Schreibman et al. Modelling, involving adult demonstration of a behaviour that follows the child's focus of interest and often demonstrates the target skill the child is to display, is ideal. Modelling is used to teach target skills from most domains: language, imitation, social, play, cognitive, motor skills, in addition to some self-care skills.</p> <p>Schreibman et al. A technique that is referred to as contingent imitation, mirroring, or reciprocal imitation and is used to increase the child's responsivity and attention to adult, imitation of adult, and continuation of the interaction, is ideal. Children with ASD respond with increased attentiveness to the adult partner when being systematically imitated.</p> <p>Prior & Roberts Use of visually cued instruction to provide the child with a predictable and readily understood environment.</p> <p>NICE Ensure there is no mental health, behavioural, environmental or physical problem is triggering or maintaining the behaviour that challenges before offering a psychosocial* intervention.</p> <p>NAC & Wong et al. (refer to Table 1)</p>
Who, where and when?	When?	<p>Prior & Roberts Intervention should start as soon as characteristics of ASD are noted and continue for as long as required.</p> <p>AHRQ In early intervention studies, younger age was associated with greater improvements, though effects were not always consistent.</p>

Section	Topic	Extracts from reviews*
	Team approach	<p>Prior & Roberts Effective programs are multidisciplinary and collaborative. Assessments and programs are provided by a number of individual service providers, such as speech pathologists, psychologists and teachers, who need to communicate and collaborate with each other to develop goals, provide intervention and evaluate progress.</p> <p>NICE Local early intervention teams should be available ‘which should include professionals from health, mental health, learning disability, education and social care services’.</p> <p>NICE People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.</p> <p>NICE Interventions should be delivered by a trained professional, and mediation by parents, carers, teachers and peers should be considered.</p> <p>NAC For selecting appropriate early intervention the judgment of the professionals with expertise in ASD must be taken into consideration. Practitioners must examine their capacity to implement interventions with integrity including his/her availability to provide adequate training and supervision of an ASD intervention program.</p>
	Professional development	<p>Prior & Roberts Teachers, therapists, and child-care personnel should be specifically trained in working with children with autism and have knowledge and skills required for their special needs. The majority of the staff in a service should have a minimum of 2 years’ experience and expertise in autism. Practitioners need to provide evidence of continuing professional development in autism as well as experience gained through previous work settings that enables them to provide evidence-based interventions for children with ASD.</p> <p>NICE Professionals working with children with autism should receive training in autism awareness and skills in managing autism.</p>
	Setting & staffing ratios	<p>Prior & Roberts Implementation of individual child goals in a small group context is not feasible with less than 2 adults for 6 children.</p> <p>NAC It is important to assess the capacity to implement an early intervention program in the chosen setting and to know if there are suitably qualified staff to supervise, train, and implement evidence-based interventions.</p> <p>Schreibman et al. There should be an emphasis on teaching in natural and varied settings, with a range of real life materials, to help broaden, or normalise, the child’s attentional focus.</p>

Section	Topic	Extracts from reviews*
Support program	Parent training	<p>NICE Interventions should be delivered by a trained professional, and mediation by parents, carers, teachers and peers should be considered.</p> <p>NICE 'aim to increase the understanding of, and sensitivity and responsiveness to, the child's communication and interaction'.</p> <p>Schreibman et al. Interventions that include parent education enhance generalisation and added learning opportunities</p> <p>A parent coaching component should be included in all interventions.</p> <p>Prior & Roberts Families should be supported to utilise strategies taught as part of the interventions at home, and empowered to encourage communication, social interaction and effective behaviour management at home and in the community.</p> <p>AHRQ recommends intensive parent training designed to modify interactions with child.</p> <p>NAC & Wong et al. Report parent training as evidence based.</p>
	Peer training	<p>NICE Interventions should be delivered by a trained professional, and mediation by parents, carers, teachers and peers should be considered.</p> <p>NAC & Wong Report peer training as either evidence based</p>
	Intensity	<p>Relevant information included in Table 5.</p>
	Quality including delivery and evaluation	<p>Prior & Roberts Quality of intervention is as important as quantity. Intensity, timing and duration of intervention should be based on individual needs.</p> <p>NAC Without the capacity to implement an intervention with integrity, even a well-designed intervention program is useless.</p> <p>Schreibman et al. 'manualization and clearly specified procedures are necessary, but not sufficient, for appropriate and effective implementation of an evidence based intervention. Additional training, including coaching and feedback, is necessary to facilitate accurate use of an intervention'.</p> <p>Schreibman et al. 'In order to determine whether an intervention is effective there must be some type of definition of its correct usage.' Therefore, early interventions offered should have fidelity of implementation assessments available to ensure integrity of treatment implementation. 'the current expectations of new intervention approaches that they include methods of measuring treatment fidelity of implementation'.</p> <p>NAC Once interventions are selected, these professionals have the responsibility to collect data to determine if an intervention is effective.</p> <p>Prior & Roberts Evaluation of intervention outcomes should be built into early intervention programs using systematic assessment of the child's social, cognitive and adaptive functioning before, during and at the end of the program.</p>

Section	Topic	Extracts from reviews*
	Comprehensive intervention programs	<p>AHRQ recommends offering extended ABA over long periods but cautions may not be effective for all children.</p> <p>Schreibman suggests that applied behavioural and developmental sciences are merged and applied in natural settings. 'use a variety of behavioural strategies to teach developmentally appropriate and prerequisite skills are ideal'</p> <p>NAC However, no intervention will universally produce favourable outcomes for all individuals with ASD.</p> <p>Schreibman et al. Interventions that encompass both focused (specific behavioural area) as well as comprehensive (communication, cognitive motor and adaptive behaviour) are ideal for children with autism.</p> <p>Prior & Roberts For young children training parents and professionals to work with the child in the key areas of social responsiveness, attention skills, early communication skills, and interactive play is needed.</p> <p>AHRQ Most of the body of literature categorised in this report as 'early intensive behavioral and developmental intervention' remains an eclectic grouping. This category of intervention presently groups different treatment approaches (i.e., developmental, intensive behavioural, centre based, and combinations), intensity (12 hours over 3 months vs. 30 hours over 1 week), and duration (weeks to years); varied inclusion and baseline assessment criteria; children of varying ages (intake age ranging from 18 months to 7 years); and many different outcome measurements over different periods of time (weeks to years).</p> <p>Wong et al. 'In a follow-up to the National Academy review, Odom, Boyd, Hall, and Hume (2010) identified 30 CTM programs operating within the U.S. These programs were characterized by organization (i.e., around a conceptual framework), operationalization (i.e., procedures manualized), intensity (i.e., substantial number of hours per week), longevity (i.e., occur across one or more years), and breadth of outcome focus (i.e., multiple outcomes such as communication, behavior, social competence targeted)'</p>
Other considerations	Co-occurring conditions	<p>Prior & Roberts Associated features of autism such as sensory processing difficulties, anxiety, and intellectual disability/learning difficulties are additional important issues needing attention.</p> <p>NICE Additional guidelines are available for ADHD, and post-traumatic stress disorder and may be a useful resource if these problems are identified in a child with autism.</p> <p>For managing anxiety, consider adapting the method of delivery of cognitive behavioural therapy so it is appropriate to each child's age and abilities and includes emotion recognition training and incorporates their special interests.</p> <p>NAC Early intervention and support options that come from sources beyond the ASD literature and should be considered when required. For example, an individual with ASD may present with behaviours associated with a co-morbid anxiety disorder in which case a well-qualified practitioner with expertise in anxiety disorders and ASD may suggest use of an intervention identified as evidence-based in the anxiety literature.</p>
	Capacity building	<p>NAC Technical support, including electronic communication (like skype) can be used to build capacity supporting practitioners and/or families. Technical support for early intervention programs can come in different forms, including electronic (like skype) connection to between experts and families in rural setting.</p>

* Reviews are NAC = NAC, 2015; Wong et al. = Wong et al., 2014; AHRQ = Weitlauf et al., 2014; NICE = NICE guidelines, 2013; Schreibman et al. = Schreibman et al., 2015; Prior & Roberts = Prior & Roberts, 2012

Appendix 5 A list from NAC of evidence based ‘behavioural interventions’ used alone or in combination

Identified component(s)

Joint Attention Intervention

Chaining

Differential Observing Response (DOR)

Forward Chaining

Function-based Intervention

Imitation Training

Reinforcement Schedule (schedule specified)

Response Interruption and Redirection (RIRD)

Repeated Practice

Standard Echoic Training

Extinction + Reinforcement

Function-based Intervention + Prompts

Sign Extinction + Differential Reinforcement of Alternative Behaviour (DRA)

Stimulus Fading + Positive Reinforcement

Choice + Task Interspersal + Positive Reinforcement

Discrete-trial Training + Natural Consequences + Error Correction

Most to Least Prompting + Natural Consequences + Activity Interspersal

Preteaching + Prompting + Positive Reinforcement

Combined Task Direction + Contingent Reinforcement + Physical Prompts + Stimulus Fading

Modelling + Prompting + Reinforcement + Redirection + Abolishing Operation Component

Prompt Delay + Auditory Scripts + Manual Prompts + Behavioural Rehearsal + Tokens

Reinforcement Pairing + Habit Reversal + GaitSpot Squeakers + Differential Reinforcement of Incompatible Behaviour (DRI)

Video Modelling + DRA + Escape Extinction + Stimulus Fading + Photo Prompting

Video Modelling + Highlighting + Prompting/Fading + Reinforcement

Video Modelling + Photo Prompts + Contact Desensitisation + Shaping + Differential Reinforcement of Other Behaviour (DRO) + Escape Extinction

Written Task Analysis + Social Scripts + Prompting + Self-monitoring + Fading

Appendix 6 Emerging interventions from Wong et al. (2014)

Augmentative and Alternative Communication Devices
Developmental Relationship-based Treatment
Exercise
Exposure Package
Functional Communication Training
Imitation-based Intervention
Initiation Training
Language Training (Production & Understanding)
Massage Therapy
Multi-component Package
Music Therapy
Picture Exchange Communication System
Reductive Package
Sign Instruction
Social Communication Intervention
Structured Teaching
Technology-based Intervention
Theory of Mind Training

Appendix 7 Reviews only including children younger than age 8 and information about level of support

Author/Title	Studies and participants	Intervention(s)
Bradshaw, J., Steiner, A. M., Gengoux, G., & Koegel, L. K. (2014). Feasibility and Effectiveness of Very Early Intervention for Infants At-Risk for Autism Spectrum Disorder: A Systematic Review. Journal of Autism and Developmental Disorders.	Total n studies included in SR: 9 Type: 4 RCTs 3 multiple baseline design 1 Quasi-experiment 1 Case series Total n: 353 This included 150 infants in experimental group and 203 infants in control groups or TAU group. Age: 4 to 30 months	Type: Interventions provided were mainly parent-mediated interventions. Most of the reviewed studies adapted intervention models such as PRT, ESDM, and Hanen's More Than Words. Intensity: range - all studies involved interventions of <2hr/wk, except one study (20hrs/wk) Duration: range 4wks to 2yrs - this was often delivered in blocks (e.g. 2 individual sessions/wk along with 9 playgroup sessions over 12mths)
Fleury, V. P., Thompson, J. L., & Wong, C. (2015). Learning How to Be a Student: An Overview of Instructional Practices Targeting School Readiness Skills for Preschoolers With Autism Spectrum Disorder. Behavior Modification, 39(1), 69-97.	Total n studies included in SR: 25 Type: 21 Single case design/case series, 4 group design Total n: 104 Age: 3 years to 5 years 11 months Diagnosis/severity: ASD	Type: 27 evidence-based practices that were identified from Wong et al. (2014) - 18 of which were found to be used and deemed effective at improving school readiness (see results) Intensity: not reported Duration: not reported
Jung, S. and Sainato D. M. (2013). Teaching play skills to young children with autism. Journal of Intellectual and Developmental Disability	Total n studies included in SR: 26 Type: 23 Single case studies, 3 Group design studies Total n: 166 (plus study that number of participants is not reported) Age: 0-8 years Diagnosis/severity: ASD	Type: Play skills using a range of methods such as video and live modelling, systematic prompting strategies, pivotal response training, restricted interests, activity schedules with correspondence training, integrated playgroup model, script training and social stories Intensity: not reported Duration: not reported

Author/Title	Studies and participants	Intervention(s)
Lieberman, R. G., & Yoder, P. (2012). Play and Communication in Children with Autism Spectrum Disorder: A Framework for Early Intervention. [Journal Articles Reports - Evaluative]. <i>Journal of Early Intervention</i> , 34(2), 82-103.	Total n studies included in SR: 12 Type: Concurrent or longitudinal correlational design Total n: 441 Age: 18–84 months Diagnosis/severity: ASD (including autistic disorder, ASD and PDD NOS) Diagnosis accepted using the following DSM-III, APA 1980, DSM-IV, APA, 1994 criteria, diagnostic tools such as the Autism Diagnostic Interview–Revised (ADI-R; Lord, Rutter, & LeCouteur, 1994), the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000), the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988), and/or developmental assessment	Type: Object play and intentional communication. Object play being broadly defined construct of play comprising non symbolic play and symbolic play behaviours with objects. Intensity: not reported Duration: not reported
Morgan, L. J., Rubin, E., Coleman, J. J., Frymark, T., Wang, B. P., & Cannon, L. J. (2014). Impact of social communication interventions on infants and toddlers with or at-risk for autism: A systematic review. <i>Focus on Autism and Other Developmental Disabilities</i> , 29(4), 246-256.	Total n studies included in SR: 26 Type: 19 single subject case studies, 7 group studies Total n: 427 Age: 10–36 months Diagnosis/severity: at risk of or diagnosed with ASD In this review, the ASD category included the following diagnostic labels: Asperger syndrome, autism, autistic disorder, PDD, and (PDD-NOS).	Type: Communication interventions across prelinguistic and emerging language developmental stages. Intensity: Not reported Duration: very limited report of this - authors only reported that the studies included a range of intensities from 'brief' to 20hrs per week.

Author/Title	Studies and participants	Intervention(s)
Oono, I. P., Honey, E. J., & McConachie, H (2013) Parent-mediated early intervention for young children with autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews. doi: 10.1002/14651858.CD009774.pub2	Total n studies included in SR: 17 Type: 17 RCTS from 1998-2012 included. 10 articles included in meta analyses. Total n: 919 Age: 17months–6yrs Diagnosis/severity: Diagnosis of ASD including autism, Asperger's syndrome, PDD and PDD NOS Where a study included children with a variety of developmental disorders, it was included only if results were presented separately for the ASD group	Type: Studies on parent-mediated interventions *14 studies had focus on parent-child interaction and child communication skills through coaching of parents by therapist *1 study had focus on massage therapy *1 focused on challenging behaviours and *1 on early intensive behavioural intervention *Also looked at moderators of treatment effect Intensity: 2-3hrs per session (in group or parent/child with therapist) Frequency of therapy range from twice a day to weekly or monthly Duration: range of 1 week- 2yrs
Patterson, S. Y., Smith, V., & Mirenda, P. (2012). A systematic review of training programs for parents of children with autism spectrum disorders: single subject contributions. [Research Support, Non-U.S. Gov't]	Total n studies included in SR: 11 Type: Single subject research design - multiple baseline Total n: 47 child participants and their primary caregiver Age: n=26 preschoolers; median age 43 mths Difference between age and language age ranged from 6-25mths; 3 also had severe ID Diagnosis/severity: 44 ASD; 1 ID, 1 Down Syndrome, 1 'autistic like symptoms' - only the 44 children with ASD were analysed in the SR.	Type: any intervention designed to increase a parents ability to support their child with ASD. These included some manualised programs including Pivotal Response Treatment, Natural Language Paradigm and ESDM. Other inventions included DTT, Reciprocal Imitation Training, milieu teaching, joint attention training, parent-implemented AAC and general case teaching. Intensity: not reported Duration: not reported
Reichow, B., Barton, E. E., Boyd, B. A., & Hume, K. (2012). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews(10).	Total n studies included in SR: 5 Type: 1 RCT, 4 Clinical Control Trials Total n: 203 Age: Participants had to be under 6yo when treatment started and assigned to their study before treatment began. Mean age at treatment entry was 30–42 months. Diagnosis/severity: ASD Participants were not excluded based on IQ or presence of comorbidities.	Type: Early intensive behavioural intervention Intensity: 20-40 hours per week Duration: follow up 1-3 years

Note: AAC = augmentative and alternative communication, ASD = autism spectrum disorder, DTT = discrete trial teaching, ESDM = Early Start Denver Model, ID = intellectual disability, IQ = intelligence quotient, PDD = Pervasive Developmental Disorder, PDD NOS = PDD Not Otherwise Specified, PRT = pivotal response therapy, RCT = randomised controlled trial, SR = systematic review

Appendix 8 Reviews including children over age eight and information about level of support

Author/Title	Studies and participants	Intervention(s)
Fletcher-Watson, S., McConnell, F., Manola, E., & McConachie, H. (2014). Interventions based on the Theory of Mind cognitive model for autism spectrum disorder (ASD). <i>Cochrane Database of Systematic Reviews</i> (3).	Total n studies included in SR: 22 Type: All RCTs (n=22) Total n: 695 Age: Up to 8 years - 13 studies Mixed ages - 4 studies Over 8 years - 5 studies Diagnosis/severity: ASD according to ICD-10 or DSM-IV or DSM-V criteria +/- ID	Type: Therapy that is either explicitly or implicitly based on Theory of Mind cognitive model of ASD. This aims to teach the ability to interpret the emotions, feelings, beliefs and thoughts of other people. Intensity: most were between 30 mins/week and 3.5 hrs/week Duration: 2 weeks to 6 months Outcomes to be measured at 3 time points: immediately post-treatment; medium-term outcome (up to 6 months post-treatment); and long term (more than 6 months post-treatment)
Ganz, J. B et al. (2011) An aggregate study of single-case research involving aided AAC: Participant characteristics of individuals with autism spectrum disorders. <i>Research in Autism Spectrum Disorders</i>	Total n studies included in SR: 24 Type: All single case studies Total n: not reported Age: 0–5 years (47%), 6–10 years (31%), >11 years (22%) Diagnosis/severity: ASD +/- co morbidity with other conditions and disabilities	Type: AAC Intensity: not reported Duration: not reported
Ganz, J. B et al. (2012) Meta-analysis of PECs with individuals with ASD: investigation of targeted versus non-targeted outcomes, participant characteristics, and implementation phase. <i>Research in Developmental Disabilities</i> , 33(2), 406-418	Total n studies included in SR: 13 Type: All single case designs There are only 9 studies in table of study characteristics – discrepancy with abstract and text Total n: 32 Age: 3–17 years Diagnosis/severity: ASD +/- ID	Type: Picture exchange communication system Intensity: not reported Duration: not reported

Author/Title	Studies and participants	Intervention(s)
Kasari C & Patterson S (2012) Interventions addressing social impairments in autism. <i>Current psychiatry reports</i> , 14(6), 713-725.	Total n studies included in SR: 34 Type: 17 Single subject research design, 17 Group design Quality ratings of weak, adequate and strong were given to papers. Total n: 743 Age: Toddlers, preschoolers, school age and adolescents (specific ages not reported) Diagnosis/severity: ASD Studies that had a mix of participants with ASD and other diagnoses were excluded	Type: Interventions aiming to improve social skills using techniques such as video modelling, play and social stories. For a full list of interventions see Table 1, p. 12 of article Intensity: not reported Duration: not reported
Knight, V., Sartini, E., & Spriggs, A. (2015). Evaluating Visual Activity Schedules as Evidence-Based Practice for Individuals with Autism Spectrum Disorders. <i>Journal of Autism & Developmental Disorders</i> , 45(1), 157-178.	Total n studies included in SR: 16 Type: All multiple baseline design (single case studies) Total n: 56 Age: 0-8 years: 6 studies (Betz et al. 2008, Bryan & Gast 2000; Cuhadar & Diken 2011; Dettmer et al. 2000; Morrison et al. 2002; Waters et al. 2009) Mixed ages: 1 study Older than 8 years: 9 studies Diagnosis/severity: ASD diagnosed using either DSM-IVTR or DSM-V criteria, range of severities	Type: Visual Activity Schedules (VAS) Intensity: not reported Duration: not reported
Knight, V., McKissick, B., & Saunders, A. (2013) A Review of Technology-Based Interventions to Teach Academic Skills to Students with Autism Spectrum Disorder. <i>Journal of Autism & Developmental Disorders</i> , 43(11), 2628-2648.	Total n studies included in SR: 29 (abstract says 25) Type: Single subject research design, Group experimental design Total n: 191 (142 of these with ASD) Age: 3–18 years (mean age 8.4 years) Diagnosis/severity: ASD–autism, PDD-NOS, Rett Syndrome	Type: Any intervention that teaches an academic skill using some form of technology. Interventions using the following were excluded because a previous study had already looked at them – alternative assistive communication instruction, unspecified assistive technology, task completion interventions, video-modelling interventions, and video conferencing interventions Intensity: not reported Duration: not reported

Author/Title	Studies and participants	Intervention(s)
<p>Lang, R., O'Reilly, M., Healy, O., Rispoli, M., Lydon, H., Streusand, W., et al. (2012). Sensory integration therapy for autism spectrum disorders: A systematic review. <i>Research in Autism Spectrum Disorders</i>, 6(3), 1004-1018.</p>	<p>Total n studies included in SR: 25 Type: Single case design, Between group design Total n: 217 Age: 2–12 years Diagnosis/severity: ASD 28% of those diagnosed with autism (55 participants) – 3 had mild ID, 15 with moderate ID and 37 with severe ID. 17 studies including children less than 8yo</p>	<p>Type: Sensory Integration Therapy (SIT) Intensity: of the studies that reported intensity it ranges from 5 minutes daily to 1 hour per session. Full details can be found in Table 1, p. 1008-1013 of journal, p. 5-10 of PDF Duration: of the studies where duration is reported the range was from 17 days to 1 year. Full details can be found in Table 1, p. 1008-1013 of journal, p. 5-10 of PDF</p>
<p>Lequaia, J., Machalicek, W., & Rispoli, M. J. (2012). Effects of Activity Schedules on Challenging Behavior Exhibited in Children with Autism Spectrum Disorders: A Systematic Review. [Information Analyses Journal Articles Reports - Evaluative]. <i>Research in Autism Spectrum Disorders</i>, 6(1), 480-492.</p>	<p>Total n studies included in SR: 18 Type: Study design for the 18 included studies is not summarised or commented on. From Table 1 (p. 483; p. 4 Adobe) the studies appear to be all single case design (which would make sense considering the type of meta-analysis performed) Total n: 43 participants Age: 3-18 years (27 participants <8yo) Diagnosis/severity: ASD, Asperger's, autistic-like characteristics, PDD-NOS</p>	<p>Type Activity schedules to decrease challenging behaviour including: * photos * line drawings * videos Aim was to promote self regulation independence, transitions or play skills Intensity Not reported Duration/follow up: Not reported</p>
<p>Raulston, T., Carnett, A., Lang, R., Tostanoski, A., Lee, A., Machalicek, W., et al. (2013). Teaching individuals with autism spectrum disorder to ask questions: A systematic review. <i>Research in Autism Spectrum Disorders</i>, 7(7), 866-878.</p>	<p>Total n studies included in SR - 21 Type: All single case designs 59% multiple baseline, 5% multiple probe, 14% non concurrent multiple baseline, 23% combination of research designs Total n: 62 Age: 2-25 years Diagnosis/severity: ASD (58% autism, 2% PDD-NOS, 40% not specified ASD) with 1 participant also having CP Most studies did not report on intellectual functioning but of those that did, 4 participants also had ID</p>	<p>Type: Any intervention aimed at teaching people with ASD to ask questions (i.e. teaching mands for information). All were multicomponent behavioural interventions. <i>What</i> questions were taught in 48% of studies, <i>Where</i> questions were 29% All 21 studies applied systematic prompting and prompt fading procedures Intensity: not reported Duration: 43% of studies collected maintenance probes, ranging from 6 days to 15 months (mean 16 weeks)</p>

Author/Title	Studies and participants	Intervention(s)
Rispoli, M., Neely, L., Lang, R., & Ganz, J. (2011). Training paraprofessionals to implement interventions for people autism spectrum disorders: A systematic review. <i>Developmental Neurorehabilitation</i> , 14(6), 378-388.	Total n studies included in SR: 12 Type: All single case design: 7 multiple baseline across participants 1 multiple baseline across settings 1 non-concurrent multiple baseline across participants 3 multiple probe across participants Total n: 39 paraprofessionals (17 rehab staff and 22 teachers assistants) & 40 students Age: Students - 16 months to 35 years (mean 14 yrs.) Diagnosis/severity: ASD (students)	Type: Training procedures for paraprofessionals included: * instructional videos * written instructions * verbal instruction * supervised practice * modelling * role-playing and supervisor feedback. Intensity: varied from 1 session to 8 sessions Follow up: varied between 2 and 11 weeks follow up measurement
Shire, S. Y., & Kasari, C. (2014). Train the trainer effectiveness trials of behavioral intervention for individuals with autism: a systematic review. [Review]. <i>American Journal on Intellectual & Developmental Disabilities</i> , 119(5), 436-451.	Total n studies included in SR: 12 Type: 1 RCT, 2 Single subject design, 9 Quasi-experimental Total n: 804 Age: toddlers to adults but primarily toddlers and preschoolers Diagnosis/severity: ASD (Autistic disorder, Asperger's or PDD-NOS)	Type: Range of behavioural interventions using Train the Trainer (TTT) techniques Intensity: some studies didn't report intensity, of the ones who did, range from 3 hours per week of intervention to 40 hours per week Duration: most studies did not report duration
Shivers, C. M., & Plavnick, J. B. (2014). Sibling Involvement in Interventions for Individuals with Autism Spectrum Disorders: A Systematic Review. <i>Journal of Autism & Developmental Disorders</i> .	Total n studies included in SR: 17 Type: 14 Multiple baseline design 1 ABAB design 2 Pre-post design (1 controlled) 10/17 studies included children <8yo Total n: 72 Age: 3–15 years Diagnosis/severity: ASD and their sibling/s	Type: A range including instruction in play skills, social skills, fine motor skills, academic skills and functional skills. The majority of studies used 1:1 instruction, although 1 study used group and pair (Pam, 2011 – pre-post design) In these, the sibling was either the instructor, the model or the co-recipient Intensity: not reported Follow up: between 1 month and 6 months

Author/Title	Studies and participants	Intervention(s)
Virues-Ortega, J., Julio, F. M., & Pastor-Barriuso, R. (2013). The TEACCH program for children and adults with autism: A meta-analysis of intervention studies. <i>Clinical psychology review</i> , 33(8), 940-953.	Total n studies included in SR: 13 Type: 6 between-group studies, 7 pre-post trials Total n: 172 Age: 2.5–32 years Diagnosis/severity: autism +/- co morbid ID and PDD NOS 7 studies looked at participants ≤ 8 , of those, 5 reported pre test mental age with the range from 20.1–57.1	Type: Treatment and Education of Autistic and Related Communication Handicapped Children Intensity: ranged from 1 hour/week–35 hrs/week Duration: from 1 week to 52 weeks.
Wang, S.-Y., Parrila, R., & Cui, Y. (2013). Meta-Analysis of Social Skills Interventions of Single-Case Research for Individuals with Autism Spectrum Disorders: Results from Three-Level HLM. <i>Journal of Autism & Developmental Disorders</i> , 43(7), 1701-1716.	Total n studies included in SR: 115 Type: 115 single case studies Total n: 343 Age: 2–32 years Diagnosis/severity: ASD (papers published after 1993 were chosen because there were consistent diagnostic criteria between DSM and ICD after DSM-IV was published in 1994 – no guarantee that included studies used these criteria in their diagnoses of ASD)	Type: Social skills interventions 'Intervention type was not examined in this study because of the difficulties of clearly categorizing the intervention type of all the studies. This was due mainly to 2 factors: lack of clear definitions for specific intervention methods, and the overlapping of similar intervention strategies across intervention programs' Intensity: not reported Duration: not reported
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. <i>Pediatrics</i> , 127(5), e1303-e1311.	Total n studies included in SR: 34 Type: 5 RCTs, 5 non RCTs, 17 case series, 7 cohort studies Studies were not included if less than 10 participants For details of study design according to intervention type, see Table 2, p. E1305) Total n: not reported Age: 0–13 years Diagnosis/severity/comorbidity: Diagnosis of ASD or if under 2yo, at risk of ASD. Detailed participant characteristics not reported in the SR (no participant characteristics table). Authors report that 1 UCLA/Lovaas RCT (Smith et al., 2000) included 28 children with mean IQ of 51. Also report IQ improvement in results, however this doesn't provide the range of IQ scores included in the studies.	Type: Interventions were divided into following categories 1. UCLA/Lovaas based interventions (range of methodologies) but all emphasised core tenets of intensive (many hrs/wk) approaches and often through 1:1 instruction 2. Comprehensive interventions for under 2yo 3. Parent training interventions Intensity: not specified for each study, however 'intensive' programs mentioned include 25hrs/wk and 30hrs/wk Duration: not specified for each study or reported as a range

Author/Title	Studies and participants	Intervention(s)
White, P. J., O'Reilly, M., Streusand, W., Levine, A., Sigafoos, J., Lancioni, G., et al. (2011). Best practices for teaching joint attention: A systematic review of the intervention literature. <i>Research in Autism Spectrum Disorders</i> , 5(4), 1283-1295.	Total n studies included in SR: 27 Type: 6 RCT, 17 Multiple baseline, 2 ABA, 1 Crossover with placebo, 1 Group design with waitlist control Total n: 367 Age: 22 months–10 years (majority preschool age) Diagnosis/severity: ASD. Co-morbid conditions included, although not specified in participant characteristics	Interventions that included an observational measure of joint attention as a dependent variable Interventions used a combination of behavioural and developmental strategies Generalisation may be occur if intervention is implemented in a play context and with natural communication partners
Note: ASD = autism spectrum disorder, ID = intellectual disability, IQ = intelligence quotient, PDD = Pervasive Developmental Disorder, PDD NOS = PDD Not Otherwise Specified, RCT = randomised controlled trial, SR = systematic review		

Appendix 9 Guidelines and information relevant to level of support

Title	Ages covered by guidelines	Methodology	Summary of recommendations relevant to level of support
Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., & State, M. (2014). Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. <i>Journal of the American Academy of Child & Adolescent Psychiatry</i> , 53(2), 237-257.	<17 years of age and all recommendations apply to children of all ages	<p>Revision of a practice parameter done in 1999 by the American Academy of Child and Adolescent Psychiatry (AACAP)</p> <p>Development of these parameters was an iterative process between the primary author(s), the Committee on Quality Issues, topic experts, and representatives from multiple constituent groups.</p> <p>This is a patient-oriented parameter, meaning it provides recommendations to guide clinicians toward best assessment and treatment practices Literature search from 1991–March 2013.</p> <p>Studies were selected for full text review based on their place in the hierarchy of evidence (e.g., randomised controlled trials), quality of individual studies, and generalisability to clinical practice.</p> <p>Search augmented by articles from expert reviewers and hand searching.</p> <p>7 recommendations are provided overall. Of these 3 are for assessment. The other 4 are for treatment.</p>	<p>The only mention of intensity in this paper is in relation to behavioural interventions: ‘Early Intensive Behavioral Intervention is:</p> <ul style="list-style-type: none"> • intensive and highly individualised, with up to • 40 hours per week of one-to-one direct teaching, • initially using discrete trials to teach simple skills • and progressing to more complex skills such as • initiating verbal behavior.’

Title	Ages covered by guidelines	Methodology	Summary of recommendations relevant to level of support
<p>Management of autism in children and young people: a good clinical practice guideline (2014) Feb;53(2):237-57.</p> <p>Authors: Veereman G., Holdt Henningsen K., Eyssen M., Benahmed N., Christiaens W., Bouchez M-H., De Roeck A., Deconinck N., De ligne G., Dewitte G., Gheysen T., Hendrix M., Kagan C., Magerotte G., Moonen M., Roeyers H., Schelstraete S., Soncarrieu M-V., Steyaert J., Tolfo F., Vrancken G., Willaye E., Wintgens A., Wouters S., Croonenberghs J.</p> <p>Publication Source: Belgian Health Care Knowledge Centre (KCE). KCE Reports 233, available via KCE website</p> <p>Publication date: 04 November 2014</p>	0-18yrs	<p>This guideline developed by Belgian Health Care Knowledge Centre on the request of parent organisations of children and adolescents with ASD, the National Institute for Health and Disability Insurance (NIHDI), and professionals caring for persons with a double diagnosis of mental health disorder such as ASD.</p> <p>The present CPG was developed by adapting international CPGs to the Belgian context based on the ADAPTE methodology (see pages 14 & 15 of full report for description of process and stakeholder consultation)</p> <p>*Authors conducted a search for clinical guidelines from 2008-June 2013, used AGREE II tool to assess guidelines.</p> <p>Authors retained only 2 guidelines as the basis for this document, the NICE guidelines (2013) guideline and HAS guidelines developed by the Health Authority of France in 2012.</p> <p>These recommendations were adapted by the Guideline Development Group from the NICE and HAS guidelines. These recommendations were agreed on by over 85% of Guideline Development Group members via a Delphi process, then stakeholders voted on the recommendations.</p>	<p>148 recommendations were developed. Recommendations are across the following 6 domains:</p> <p>Domain 1: Experience of care and the organisation and delivery of care</p> <p>Domain 2: Interventions aimed at core features of autism</p> <p>Domain 3: Interventions aimed at behaviour that challenges</p> <p>Domain 4: Intervention aimed at associated features of autism and coexisting conditions</p> <p>Domain 5: Interventions aimed at improving the impact of the family</p> <p>Domain 6: Adverse events associated with interventions</p>

Title	Ages covered by guidelines	Methodology	Summary of recommendations relevant to level of support
<p>Management of Autism Spectrum Disorder in Children and Adolescents - Clinical practice guidelines</p> <p>Authors : Malaysian Health Technology Assessment Section (MaHTAS), Medical Development Division, Ministry of Health Malaysia</p> <p>Publication date : These guidelines were issued in July 2014</p>	<p>Children and adolescents with ASD who are less than 18 years of age</p>	<p>This document was intended to guide health professionals and relevant stakeholders in primary and secondary / tertiary care of autism including: psychiatrists, psychologists, allied health professionals, doctors, educators and policy makers.</p> <p>Recommendations developed to address 27 clinical questions.</p> <p>Used Grades of Recommendation from The Scottish Intercollegiate Guidelines Network (SIGN)</p> <p>Systematic literature search for research from dates between 1994– early 2014. Reference also made to NICE (2011) guidelines, SIGN (2007) guidelines and New Zealand Ministry of Health (2008) guidelines which the developer evaluated with the AGREE II tool before using them.</p> <p>Recommendations were developed based on literature by the Development Group and sent out to external reviewers.</p>	<p>RECOMMENDATION 6</p> <ul style="list-style-type: none"> • Applied Behaviour Analysis should be considered in the management of children with autism spectrum disorder. (Grade A) Authors note that with regard to ABA, there is inadequate evidence to pin-point specific behavioural intervention approaches to be most effective for individual child with ASD.

Title	Ages covered by guidelines	Methodology	Summary of recommendations relevant to level of support
<p>Best Evidence Statement: Adding home-based services to complement centre-based intervention for children with autism</p> <p>Author : Johnson, A., Cincinnati Children's Hospital Medical Center, Best evidence Statement no: 131, pages 1-6, Publication date: 2/6/13.</p>	<p>Target Population for the Recommendation:</p> <p>Inclusion</p> <ul style="list-style-type: none"> -Children under the age of 6 years old with ASD or pervasive developmental disorder — not otherwise specified -No exclusion criteria for children with dual diagnosis 	<p>This is a best evident statement issued to address a specific clinical question, it is not intended to be a comprehensive practice guideline.</p> <p>Author performed a literature search for research between 1980– February 16, 2012</p> <p>Table of levels of evidence used to grade studies used in statement (1A, 2A, 3A etc.) Author relies on 5 studies on which to base recommendations</p> <p>This Best Evidence Statement has been reviewed against quality criteria by 2 independent reviewers from the CCHMC Evidence Collaboration, see p. 5,6 for grading of the recommendations</p>	
<p>Maglione, M. A., Gans, D., Das, L., Timbie, J., & Kasari, C. (2012). Nonmedical Interventions for Children With ASD: Recommended Guidelines and Further Research Needs. <i>Pediatrics</i>, 130, S169-178.</p>	<p>Participants mentioned in these guidelines are 'children and adolescents', and the reader is directed to the full report for methods, included studies, participant characteristics.</p>	<p>Primary area of focus of these guidelines were comprehensive programs, however the expert panel also made recommendations about social skills and communication programs.</p> <p>'The guidelines were developed by a Technical Expert Panel (TEP) consisting of practitioners, researchers, and parents. A systematic overview of research findings was presented to the TEP; guideline statements were drafted, discussed, debated, edited, reassessed, and presented for formal voting.'</p> <p>The members of the expert panel were asked to vote whether they considered each recommendation 'weak' or 'strong.' The percentage of TEP members who felt the guideline statement should be 'strong' was tallied.</p>	<p>Evidence finding: 'moderate evidence that greater intensity (hours per week) and greater duration (in months) lead to better outcomes'</p> <p>'The vast majority of high quality behavioral interventions found in the literature required 20 to 40 hours of treatment per week ...'</p> <p>'... 1 review of behavioural interventions suggests that treatments are more effective during the first 12 months following initial assessment.'</p> <p>Guideline 4: Children with ASD should be actively engaged in comprehensive intervention for a minimum of 25 hrs/week throughout the year. Rating: 56%</p>

Title	Ages covered by guidelines	Methodology	Summary of recommendations relevant to level of support
<p>Myers SM, Johnson CP; American Academy of Pediatrics Council on Children With disabilities. Management of children with autism spectrum disorders. Pediatrics. 2007 Nov;120(5):1162-82. Epub 2007 Oct 29.</p> <p>Clinical Report: Management of Children With Autism Spectrum Disorders. Pediatrics. 2007;120(5):1162–1182. Reaffirmed September 2010.</p> <p>Clinical Report: Management of Children With Autism Spectrum Disorders. Pediatrics. 2007;120(5):1162–1182. Reaffirmed August 2014</p>			<p>Provision of intensive intervention, with active engagement of the child at least 25 hours per week, 12 months per year, in systematically planned, developmentally appropriate educational activities designed to address identified objectives.</p> <p>Low student-to-teacher ratio to allow sufficient amounts of 1-on-1 time and small-group instruction to meet specific individualised goals.</p>

Appendix 10 Research recommendations

Populations - diversity	<p>NAC: Information about ethnicity, family structure, language barriers and other factors that could influence intervention effectiveness is needed so that modifications can be made if needed.</p> <p>AHRQ: the intervention research often fails to describe whether treatment effect is modified by family, culture, available resources, and stress. Early intensive behavioural and developmental approaches therefore warrant further research to understand individual response and benefit in the short and long-term across heterogeneous populations.</p> <p>Wong: 'Because a needed feature of future intervention research is to include a more diverse set of participants than has occurred in the past and examine differences in treatment outcomes that may occur. This issue of diversity incorporates race/ethnicity but extends also to gender and socioeconomic diversity.</p>
Populations - High risk siblings	<p>NAC: A synthesis of evidence about interventions for high risk siblings is needed.</p>
Assessing effectiveness	<p>Schreibman: Data should be collected to examine the success of an intervention as a whole.</p>
Fidelity	<p>Schreibman: Understanding the necessary procedural fidelity of individual components within treatments/treatment packages.</p>
Implementation	<p>AHRQ: Because the treatment process for ASD is typically intensive and often requires highly specific and well-trained individuals to deliver to fidelity, questions of feasibility and accessibility are pertinent but largely understudied.</p> <p>AHRQ: Explicit evaluation of treatments of highest impact in community settings as well as studies explicitly evaluating settings and providers would benefit our ability to understand impact and implementation.</p> <p>AHRQ: Evaluations of intervention delivered by community providers are important for comparing effects of such approaches with those of interventions delivered in controlled research environments. Such evaluations are complicated by the complexity of community systems and methodologic challenges including creating similar treatment and control groups and maintaining</p>

	<p>fidelity; however, they will be increasingly valuable for scaling intervention for ASD.</p> <p>Schreibman: Utilising innovative methods to implement and sustain research-based NDBIs in the context of community programs serving children with ASD.</p> <p>Schreibman: Developing new methodological approaches to test treatment strategies for improving the outcomes of NDBIs for all children, including children who are slow or poor responders to a specific treatment.</p> <p>NICE: What is the value of a key worker approach (defined by protocol and delivered in addition to usual care) for children and young people with autism in terms of parental satisfaction, functioning and stress and child psychopathology?</p>
Information to indicate need for change of intervention	<p>AHRQ: Further, our understanding of early indicators of treatment response is extremely limited, such that evidence-based changes in treatment planning based on an observed response or lack thereof are not possible. This is important to parents, providers, and families as they often want to know not only when a treatment is working, but when limited benefit of treatments may suggest pursuing other treatment options.</p>
Moderators and mediators of interventions — including child characteristics and providers	<p>Schreibman: Increased emphasis on larger scale and more contemporary RCT designs that can address moderators and mediators and efficiency of treatments.</p> <p>AHRQ: Child characteristics like baseline cognitive, language, adaptive skill, and ASD symptoms may correlate with treatment outcome; however, such correlational data provides limited information in making predictions of what treatments will work best for individual children. A critical area for further research is understanding which children are likely to benefit from particular interventions.</p> <p>AHRQ: To date, studies have failed adequately to characterise interventions or children receiving intervention such that we can better understand which children are most likely to experience positive outcomes and why.</p> <p>AHRQ: Also important in addressing this gap is improving our currently limited understanding of the effects of provider training and provider characteristics on outcomes of treatment.</p>
Outcome measurement - change	<p>AHRQ: A primary methodological concern relates to outcome measurement. Intervention research in the field of ASD has often relied on various and differing ways of marking change, which has limited our ability to understand change within and across individual studies. Research on appropriate methods to capture meaningful change will be critical to advance our understanding of behavioural interventions.</p> <p>Schreibman: Measurement of intervention outcomes that represent meaningful change.</p>

Outcomes measures – parent v other types	AHRQ: Parent or teacher reports of functioning may be useful as a preliminary index or used potentially as a component of a broader measurement strategy attempting to index change, but reliance these ratings provides only an intermediate and often biased assessment of change, with potentially very limited value to understanding how interventions translate in to meaningful long-term functional outcomes.
Long term outcomes	AHRQ: Research is lacking on the durability of treatment gains and approaches needed to maintain gains.
Specific components for combined interventions	<p>Schreibman: Empirical analysis of the active ingredients within multicomponent interventions.</p> <p>AHRQ: It is unclear how similar groups of children will perform at differing levels of intensity of interventions or different treatment approaches and methods.</p> <p>AHRQ: intensive, comprehensive intervention strategies are by their very nature often multi-component. Data on whether specific functional components of the interventions drive effectiveness are currently unavailable as are data on mediators of change.</p>
Specific interventions – relevant to early intervention	<p>NICE: Are comprehensive early interventions that combine multiple elements and are delivered by parents and teachers (for example, the Learning Experiences model – an alternative program for preschoolers and their parents – effective in managing the core symptoms of autism and coexisting difficulties (such as adaptive behaviour and developmental skills) in preschool children?</p> <p>NICE: Is a group-based parent training intervention for parents or carers of children and young people with autism clinically and cost effective in reducing early and emerging behaviour that challenges in the short- and medium-term compared with treatment as usual?</p> <p>Wong: ‘While the evidence for comprehensive treatment programs for toddlers with ASD is expanding (Odom et al., in press), there is a need for moving forward the research agenda that addresses focused intervention practices for this age group.’</p> <p>NAC: Technology-based Intervention, require additional research.</p> <p>NAC: Music therapy requires additional research</p>
Specific intervention – not early intervention specific	<p>NICE – Sleep: Is a sleep hygiene intervention or melatonin clinically and cost effective in the management of sleep onset, night waking and reduced total sleep in children (aged 4–10 years) with autism?</p> <p>NICE – Anxiety: What is the comparative clinical and cost effectiveness of pharmacological and psychosocial interventions for</p>

	<p>anxiety disorders in children and young people with autism?</p> <p>AHRQ – Social skills and cognitive behavioural interventions: social skills interventions and cognitive behavioural interventions for anxiety have demonstrated short-term benefit for some children with ASD. However, this literature focuses almost entirely on older children with ASD and intact cognitive skills. Understanding the impact or lack thereof of such interventions for others with ASD is important.</p>
Comparisons of different interventions and combinations of interventions	<p>AHRQ: There is a lack comparisons of interventions and combinations of interventions (e.g., medical interventions, with behavioural interventions, with educational interventions, with allied health interventions), despite the fact that most children are undergoing multiple concurrent treatments.</p>
Systematic reviews of medical and allied health interventions	<p>AHRQ: Systematic reviews of studies of interventions in other categories (e.g., medical, allied health) would provide useful information for clinicians, researchers, policy makers, and families.</p>

* Reviews are NAC = NAC, 2015; Wong = Wong et al., 2014; AHRQ = Weitlauf et al., 2014; NICE = NICE guidelines, 2013; Schreibman = Schreibman et al., 2015

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