

THE AUTISM RESEARCH TOOLKIT



A research-aware resource for
professionals working with Autism
Spectrum Disorder Interventions: Part 1

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A RESEARCH-AWARE RESOURCE FOR PROFESSIONALS WORKING
WITH AUTISM SPECTRUM DISORDER INTERVENTIONS: PART 1

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Background

Over a year ago, the four of us embarked on a goal to write a research-aware resource for professionals who are working with children with Autism Spectrum Disorders (ASD). Why did we think this was a good idea? The idea came from a common experience. We each have a background in psychology but we now work in different sectors, two of us in university research and two in different charities. Although we were each working with different groups of professionals, we were all acutely aware of a gap between research and practice. Our goal was to try to narrow that gap.

There are a vast number of untested interventions for autism in the marketplace. Service commissioners make decisions to select particular intervention programmes and they are not always aware or able to make use of research evidence when they make these decisions. Professionals use interventions that have been selected for them or that they themselves select, they may adapt these interventions or else devise new interventions of their own but may not have access to measurement methods to test for change. Parents also select interventions themselves on the basis of claims from the internet. On the other hand, a fundamental requirement for researchers working in science and social science is to apply testing standards to ensure reliability. Research studies test ideas to produce evidence and to test whether or not change is actually happening. But researchers are not sharing this expertise with people on the ground. And they need to if we are going to make progress to help children with ASD. We need to develop measure and test interventions in a systematic way.

We have called this resource the Research Toolkit. It is part of a set of research-aware resources for professionals and parents that we are developing as part of a knowledge exchange initiative supported by the Economic and Social Research Council. We hope you find it useful. Please help us to test this toolkit by sending us your comments and feedback to the email address below and/or connect to the new open access site *the Autism Research Policy Practice Hub*, launching in September 2013.

Louise White, Sue Leekam, Sarah Shenow, Gina Gómez de la Cuesta.

Feedback welcome: email warc@cardiff.ac.uk or autismrpphub@cardiff.ac.uk



● ● ● RESEARCH, POLICY, PRACTICE

The Research Toolkit for professionals working with Autism Spectrum Disorder (ASD) Interventions

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1.0 Introduction

1.1 Who is this research toolkit for?

Are you a practitioner, service manager or government/charity advisor working in the field of Autism Spectrum Disorder (ASD)? Do you listen to claims in the media or internet about “new evidence into ASD” and ask if these claims are true? Do you work with health or education intervention programmes and need to be able to recommend a particular intervention for an individual clinic, school or community, but are not sure what evidence to rely on? Or would you like to carry out research on ASD in your own area of practice?

If you’ve answered yes to any of these questions, this toolkit is for you. The goal of this research toolkit is to increase your confidence about research by increasing your research-awareness. We’d like to equip you with some research ‘tools’ to help you monitor or make decisions about the research you read. We believe that there is a big gap between research and practice due to a lack of understanding about the research process itself. So what we are aiming to do is to advance research-awareness a little further.

1.2 What’s in it for you?

Professional work in ASD draws on the expertise of many different perspectives. You might be a psychiatrist, paediatrician, psychologist, occupational therapist, educational psychologist, language therapist or social worker in a multidisciplinary diagnostic or intervention team. Or you might be a policy maker, care provider or teacher, all of whom play a significant part in the life of an individual with ASD. So what is in this Research Toolkit that is relevant to you in particular?

Where are you coming from?

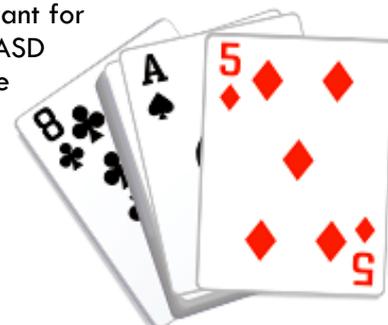
Different perspectives in health and social care in ASD reflects a history of difference in medical versus social approaches to disability. The traditional *medical approach* is to focus on the biology and psychology of autism. The traditional *social approach* is to focus on the environment and particularly the social environment or organizational practices. These historical differences between professions can also be seen in the field of research, reflected in the distinction between medical science and social research. So whether your background comes from the medical or social approach, is the toolkit applicable to you?

Be aware of your assumptions!

We start with a key rule for research awareness which is “Be aware of your own assumptions!” We know that neither of the extreme positions taken by the medical and social approach is correct. The reason is because biology and environment are constantly interacting across a person’s life. This means that both approaches are complementary and we need to cross the extremes of both approaches. This is why multidisciplinary work in ASD is so important. However assumptions coming from these historical approaches still influence the method of both professional practice and of research.

Putting your cards on the table.

So it is important to be aware of where you are coming from, and to make your assumptions explicit. We ourselves have been trained in the scientific method that is associated more with the medical model. This means that the Research Toolkit reflects the values and assumptions of medical science. But whether you have a science or a non-science background we hope that this toolkit will be relevant for you. Our goal is that you will become more aware of when an intervention for ASD needs to be evaluated according to stringent scientific conventions and why these criteria are important in comparison to judging an intervention on the basis of a completely different set of criteria such as anecdotal evidence, opinion or interest.



2.0 Why research matters for good practice in ASD

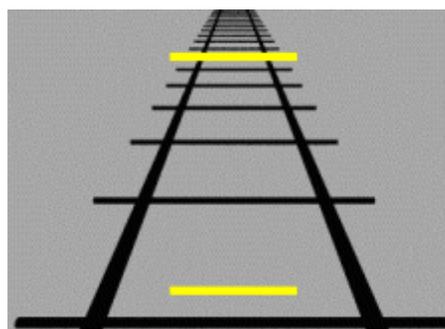
2.1 How do you develop evidence-based practice?

How do you know if an intervention for ASD ‘works’? If you have tried a technique with one child and it worked, how do you know whether it was suitable for another? If you are a service manager who needs to recommend a particular intervention programme, what criteria would you use to decide this? Many practitioners say that they use evidence all the time. They see for themselves what works, because they notice a change in a child. They see the evidence with their own eyes. This could be described as practice-based evidence. This kind of evidence might be thought of as a hunch or as an observation of what might work and make a change. It also might provide the basis for a ‘pilot study’ for initial testing out phase. However many interventions for ASD are stuck at this hunch phase and make claims that are far too sweeping. Would you take a drug for a health condition if it had not been properly developed and tested?

Question: Why does research matter for those who are working in practice?

Answer: Because practitioners and policy makers need to rely on solid, reliable evidence in order to know what actually works and so to make judgements about which programmes of support and intervention are suitable.

Example: Look at the yellow lines



Q. Are the yellow lines the same or different lengths?

A. They are the same.

In the diagram, the top line probably appears longer. Our brain is telling us they are different lengths because the top line appears further away. Our brains can fool us about simple sensory things like this. Even if we have seen something with our own eyes, it is not necessarily as it seems! Therefore we should not just use our impressions or feelings about a patient’s or client’s behaviour before and after an intervention to decide if that intervention works. We need to take objective measurements.

(Many thanks to Prof David Evans of Bucknell University, USA for this example)

This is why we advocate evidence-based practice. If good intervention practice is not guided by sound research design and measurable evidence (evidence-based practice), we simply do not know what exactly it is that is ‘working’ to make that difference. We don’t know if there would have been a change for the better even without the intervention or if another one might have been better, and we don’t know how it works or who it works for. Therefore evidence from good, reliable research is a ‘must’ before you accept any program as an effective intervention for ASD.

2.2 What does it mean for an intervention to 'work'?

What criteria would you use to assess whether it makes a difference? The first criterion is that there is a change. But the change also must be measurable. If the intervention cannot be shown to produce a measurable change in behaviour then one cannot say that it 'works'. But the measurable change produced should also be relevant to the claims of the intervention. If a measurable change can be reported in a parent's confidence in working with their child in the intervention, that may be a beneficial outcome, but if the goal of the intervention is to improve language skills in the child, what do you conclude?

Even if we find a measurable change, we need to be as sure as possible that it is the intervention and nothing else that is driving any change in behaviour. Behaviour, especially behaviour of children, changes over time anyway without any intervention. Also, people's behaviour is remarkably sensitive to being watched and attended to, so any intervention or increased attention towards a child is likely to make a difference regardless of what it is. This is why you need to compare the behaviour of the children who had the intervention with the behaviour of a similar group of children who have not received the intervention. The important thing is that even when somebody thinks they are not influencing the outcome of a study, they are likely to do so even unconsciously.

So, when you are evaluating a group-based intervention study you should be wary of any research design that does not include a comparison group that does not have the interventions. It is also important for the researcher to take pre-test (baseline) measures and compare them with post-test (outcome) measures. It is best to take these measures for both the control group as well as the treatment group. Researchers should be concerned about getting as accurate as possible measure of any changes in behaviours.

Summary

We need to develop evidence-based practice because formal research evidence is the only way to demonstrate that an intervention 'works'.

Even when we have seen something with our own eyes, we may not have accurately understood the situation.

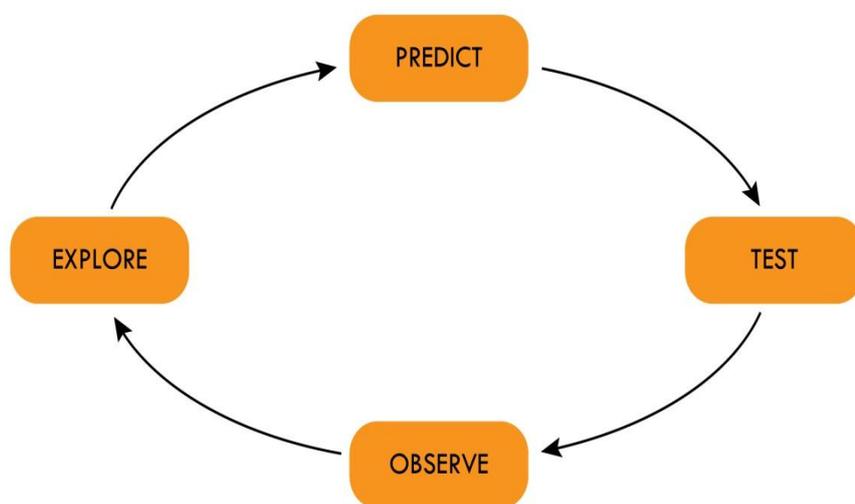
An intervention 'working' means that it causes a measurable change in behaviour that is not due to any other factor.

3.0 Is it research and should I believe it?

3.1 What is research?

The term “research” is often used in a very broad way. In fact any data collection or information-seeking activity can be loosely described as research. So activities such as looking for information on the internet, making enquiries, trying out new products - all these could be described as research activities. It is important to make a distinction between these kind of **data-gathering** activities, and **research activities** that are being carried out as part of formal research method. Research or data-gathering for the purpose of informing a campaign is not the same as research to determine whether an intervention is effective. Data gathering can be based on unsystematic observations. We have tried to describe this distinction in “The research cycle” diagram in Figure 1. So when anyone tells you that they are carrying out research make sure that you check the status of their research activity. If their ‘research’ is one of the data-gathering activities listed above, or involves unsystematic or anecdotal observations, then it is not formal research and you need to question the conclusions that can be drawn from this ‘evidence’.

FIGURE 1: THE RESEARCH CYCLE: WHAT GOES AROUND COMES AROUND



Example: The cycle of stages needed for research.

1. Let's start with **observe**. Imagine that you are a speech and language therapist working with a child who has very little communication or eye contact. You notice that when you match this child's actions by imitating him, you experience more engagement and interest from the child.
2. You then **explore** this, taking observations in different ways. You ask, “What is this experience of engagement? How can I best measure it?” You look at different methods used in other research and select a reliable measure, such as the child looking to your eyes, which can be measured reliably.
3. Then you **predict** that “children who are poor at communication and make little eye contact will look at another person's eyes if that person matches or imitates the child's actions”.
4. Then you need to **test** this prediction. So you set up a play session. The child and another therapist play together, and the therapist imitates the child. Importantly the therapist does not know what your prediction is which reduces the therapist from unconsciously influencing the result and biasing the conclusion. You compare this with a situation where the therapist does not imitate. Is there a measurable difference in the child's behaviour? Do you see this effect across different sessions, across different therapists, across different children?

BOX 1: Evaluation, audit and research – what’s the difference?

People often confuse research, evaluation and audit.
To tell the difference between them it is best to focus on their aims

Scientific Research

As a rule of thumb, you can assess whether a project is research if its aim is to discover new knowledge that can be generalised to different situations or across different people. For example, if a new intervention is being introduced within clinical services in the UK to improve the social and communication skills of very young children with ASD, the research question might be, “Does this new intervention reduce symptoms of ASD any more effectively than an intervention that would be normally be given by these services?” The aim of the research project is to find out if the intervention brings measureable change to social and communication skills, in a way that is true beyond the project’s participants and generalisable to other children.

Audit

The aim of an audit is to measure the performance of an organisation against certain benchmarks, possibly financial or procedural. Its purpose is to check whether a service meets a predetermined benchmark or standard. Given the example about intervention services above, a possible audit question might be: How many children are referred to clinics with social and communication impairments on a yearly basis, comparing figures across years?

Service Evaluation

A service evaluation also aims to study a service that is already in place, meeting local needs rather than producing results that can be generalised to other settings. However, a Service Evaluation is a mechanism to provide comprehensive information about the performance and outcome of a service. The purpose of a service evaluation may be to describe people’s experience and impressions of having been part of that service. So for the intervention service example above, the evaluation questions would be: How was the new service experienced by the families who took part and what were the views of the practitioners and organizations who delivered it?

More Information: http://www.apcrc.nhs.uk/evaluation/documents/general_toolkit.pdf

Anecdotal Evidence

This is 'word of mouth' evidence. For example, someone might say, "Try this intervention, it worked for my son, and my friend's son." The aim of anecdotal evidence is to pass on experience. Anecdotes are opinions and experiences of a small group of people. They are based on personal experience and are a powerful form of information. Anecdotal evidence is often used in publicity material and can be very appealing. Anecdotal evidence may be useful to get some scientific evidence started or to start a media campaign. But anecdote is NOT enough to demonstrate that an intervention 'works'. A report of personal experiences is simply a report of personal experience and does not involve systematic measurement. It is important to systematically measure not only change that is happening during the intervention but also other things that are happening at the same time as the intervention, because these things themselves might explain the change. For example, a child's improvement coincides with increase of structure in the school timetable or when grandmother comes to visit. Who knows what really caused the change? Therefore, it is simply not possible to draw conclusions about what works on the basis of an anecdote.

Sometimes an anecdote will appear as larger text embedded in a written report. Your eye is drawn to the larger text and it might seem that the anecdote reflects what is most important in the report. Be aware of these kinds of powerful attractors when your attention is drawn to them in a report or summary of findings. They often foreground your attention but do they really represent the evidence shown elsewhere in the report? If this is anecdotal evidence and not systematic research should you believe it?

"Ikanesol is the best programme that my child ever had. It totally changed his behaviour."

TABLE 1: RESEARCH, AUDIT AND EVALUATION

| Type of Activity | Formal Research | Audit | Evaluation | Anecdotal Evidence. |
|------------------|---|--|--|--|
| Aims: | creates new knowledge that is generalisable beyond a specific service | checks whether a service reaches a standard | finds out what performance or outcome a service achieves | finds personal experiences/opinion to support a campaign |
| Measures: | compares groups against a research hypothesis | compares against a predetermined standard | measures aspects of a service independently of a standard | measures views and experiences of a small group of users. |
| Uses data | that are additional to the service and uses original analysis | that are collected as part of the service | that are collected as part of the service | that are testimonials, personal accounts, service user feedback |
| Outputs: | information that will test predictions generated from theory or previous evidence | information to update standards of a specific, existing service delivery | information to judge the performance of a specific, existing service | information to support a view of a service that may be used as part of a media campaign or a basis for research. |

A research project needs to be designed according to a set of scientific conventions. These conventions are based on strict rules about how the project is designed, how the data are gathered, how results are reported and how they are interpreted. The quality of evidence that you read about and the extent, to which you can trust a piece of evidence, will depend on how carefully and systematically the data have been collected – in terms of how these conventions have been followed. In Part 2 of the ASD Research Toolkit, we will be able to tell you more about the rules of research and how to follow them.

So if the data collection activities of evaluation or audit projects are not part of a research project, does that mean that we should treat these activities and evidence as the unsystematic 'data-gathering' activities as described in Section 1.1? The answer is no. Both research and evaluation involves addressing clearly defined questions using systematic and rigorous methods (NHS Research and Development Forum, 2006). So although audit and evaluation serve different purposes and have different aims, they may use similar methodologies. For example, an evaluation project may develop a simple interview or questionnaire to explore issues related to a service user's experience.

And when you are deciding whether a project that you read about is a good evaluation project or good research project, you should be scrutinising whether those methodologies have followed the required conventions. You also need to consider whether the interpretation of these data is really accurate and undistorted. We talk more about biases of interpretation in the Box "Beware of bias".

REMINDER: So when you are deciding whether it is research, consider the aims of the project. Remember: Research aims to obtain new knowledge that is generalisable and can be applied across many people/instances/situations.

3.2 Different Types of research

Types of research

Once you've established that your project of interest is actually research and not something else, what kind of research are you dealing with? Even when you know that something is research it can still be difficult to define! Table 2 shows three very different types of research activity.

Scientific research in autism aims to explain aspects of the world or the individual that might be challenging for a person with ASD and how they might be changed to create improvements. Research studying the brain, the sensory system or children's aggression with others might be all described as scientific research projects. There is no policy agenda behind these projects. They aim to 'find out' (observe) or to test a theoretical prediction about what might be happening.

Policy research is different. It is commissioned to answer a strategic question and is influenced by those who want to change policy and achieve particular results.

Action research is different again. It deals with real-world problems and issues in an organizational setting. A problem is identified, a change (action) is implemented and the results of the change are then evaluated. It is seen as a circular process where the findings are put into practice and affect further research.

These different types of research are also influenced by the distinction between medical and social research that we talked about earlier. Each of these research approaches may draw on different methods. All this might sound very confusing! However, whether you are a medical scientist carrying out biological or psychological research or a social scientist carrying out social policy research, the overall **purpose** of research is the same. The purpose of research is to describe and ultimately explain phenomena – things that happen in the world.

REMINDER: Whether it is scientific, social policy or action research, remember that researchers have a common purpose to describe and explain phenomena.

TABLE 2: DIFFERENT TYPES OF RESEARCH

| Type of Research | Scientific Research | Policy Research | Action Research |
|------------------------|--|--|--|
| Aims | To increase/create new knowledge | To change policy | To find specific answers within an organisation |
| Measures | Can be exploratory (inductive) or testing a hypothesis (deductive) | Can be exploratory (inductive) or testing a hypothesis (deductive) | Can be exploratory (inductive) or testing a hypothesis (deductive) |
| Uses data from? | From outsiders (participants selected to reduce bias) | From Insiders (practitioners) and outsiders (participants) | From Insiders (practitioners) |
| Outputs | information that adds to knowledge | Information that changes policy | Information that leads to more changes in practice. |

Inductive thinking starts with specific examples and uses them to develop a general theory. It is bottom-up.

In contrast, **deductive thinking** starts with a theory or general statements, and specifically tests each of its components. It tests specific hypotheses about the component parts of a theory. It is top-down.

DIFFERENT TYPES OF RESEARCH: A DETAILED ANALYSIS

Further examples of social policy research compared with basic science research:

What kind of research?

Take two examples;

1. A social policy researcher wants to discover whether the provision of diagnosis services for adults with ASD will have effects on other services, for example on the mental health services.
2. An experimental psychologist wants to test whether training parents to play with their children in one way (using particular social communication strategies), improves individual children's language skills more than training them to play with their child in another way (by parent focusing on modifying behaviour without using these social communication strategies).

Have a look at the Research Cycle diagram on pages 8 and 14. Both policy and experimental psychology research examples fit into this research cycle. The policy research (Example 1) would belong at the exploratory, inductive end of the cycle because at this stage there is no hypothesis based on theory or previous evidence. We might assume that having a diagnosis of ASD and post-diagnostic counselling would help the individual and those around him or her to come to terms and adapt to the condition, leading to greater adaptation to circumstances that might otherwise create extreme anxiety and/or depression. So the demand for mental health services might reduce. However, having a diagnosis might lead an individual to become more aware of a problem of anxiety or depression related to their diagnosis and therefore to seek treatment for it. Therefore the demand for mental health services might increase. We don't yet have a clear prediction, so the research would involve collecting observations and data across measures that will be sensitive enough to capture these different interpretations and pilot studies might be carried out before we could enter the predict and test phase of the cycle.

The experimental psychology research project (Example 2, Figure 2 Page 15) we described is placed at the deductive or "test" side of the research cycle. It tests a specific prediction or hypothesis, that there will be a difference between two different intervention conditions, and explains this difference in terms of precise elements which are provided in the intervention condition and controlled for in the control condition. The logic for this prediction is provided by well-known theories in child development showing that particular types of mother-child interaction make a positive difference to a child's language learning.

While in the examples we've given, the experimental psychologist's study provides a deductive (top down) test of a hypothesis, and the policy research provides inductive (bottom-up) data, this could easily be reversed. Research by medical scientists is also inductive and research questions can also be placed at the descriptive end of the research cycle as researchers explore the characteristics of the phenomena that they are interested in before setting up hypotheses. Likewise the policy project might start with descriptive rather than explanatory data but these observations can then be used to build up clear hypotheses 'bottom up' (inductively) which can then be tested deductively (top down).

FIGURE 1: THE RESEARCH CYCLE

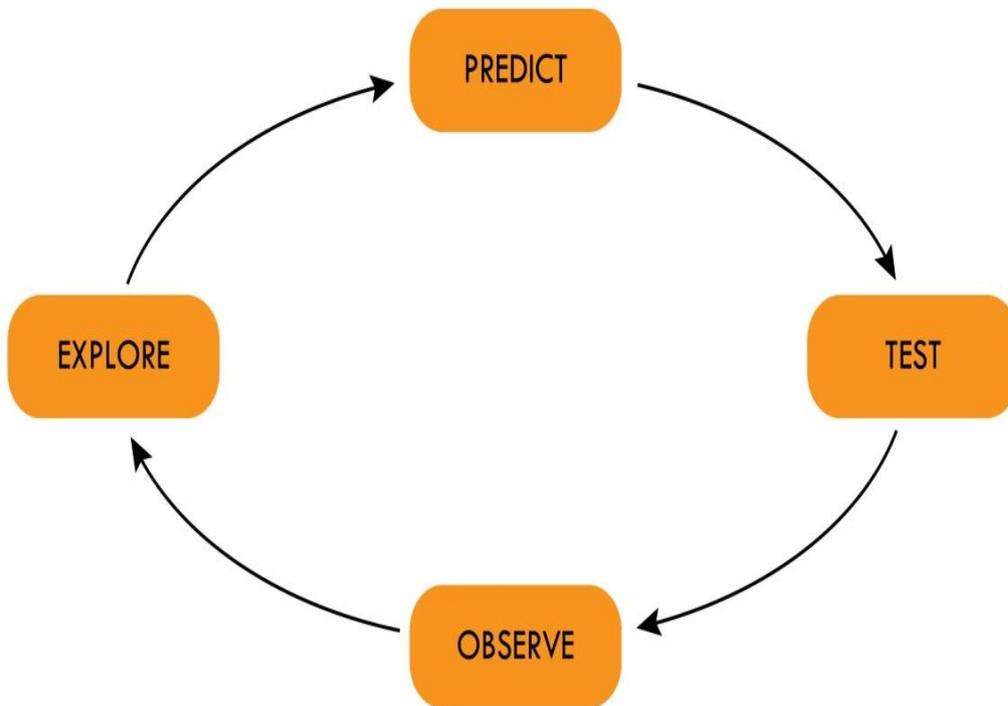
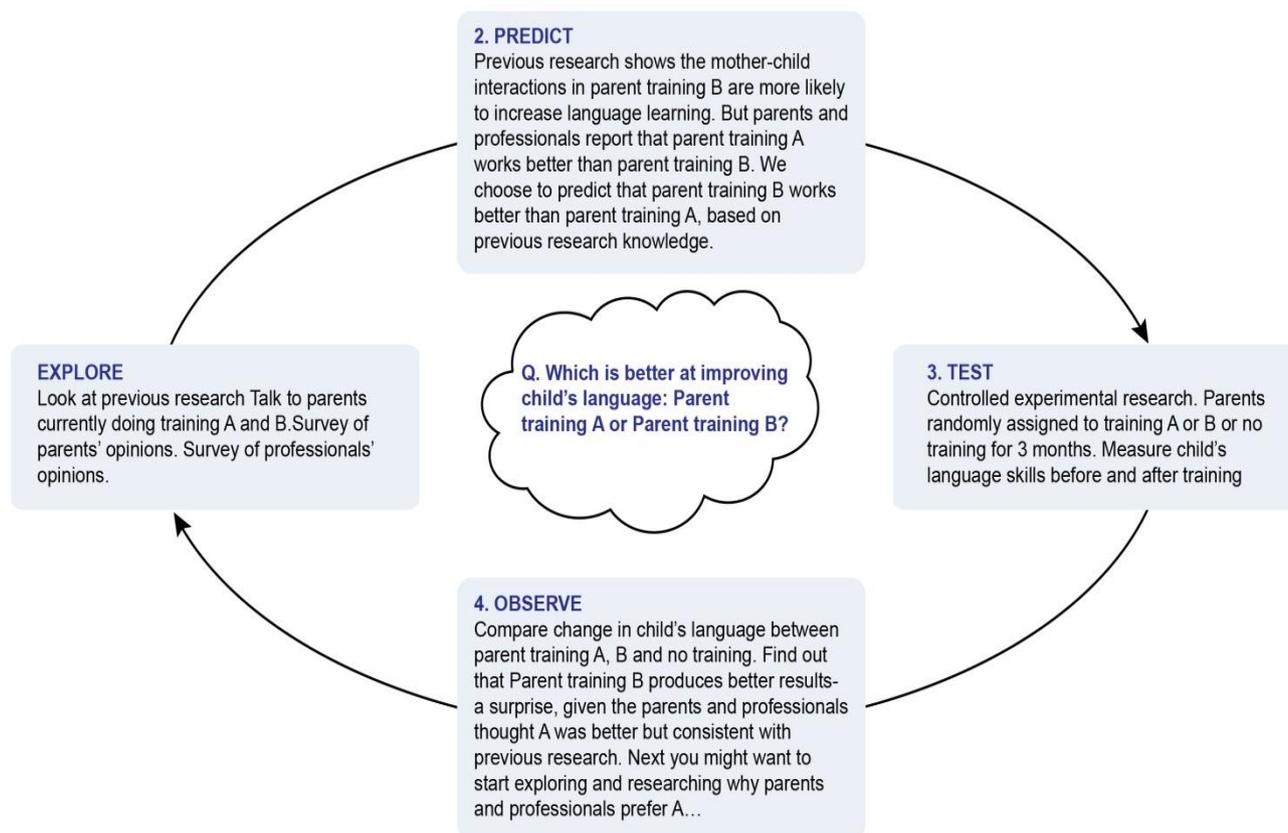


FIGURE 2: AN EXAMPLE OF A RESEARCH CYCLE



3.3 Take home message: So should I believe it?

These examples show that there are similarities in research principles across different types of research from basic science to policy research. In the section above we have also stressed that all research should have strict standards with regard to how data are collected, reported and interpreted. The important difference between basic science and policy-oriented research however is what the research will be used for. The first priority for basic science research is for it to be used to increase knowledge about the causes and characteristics of ASD. Basic science research findings may have major impact on both practice and policy but the project is not originally designed for this purpose. However, the opposite applies for policy research. The first priority for a policy research project is to answer those questions that will change policy.

No research is value-free and every researcher has implicit assumptions that he or she takes into the research field. However, when you are reading research proposals and research evidence, it is important to be aware of how research can be both used and misused. Be always aware of researcher and reporting bias [See Bias Box].

BIAS BOX.Researcher and reporting bias:

A newspaper has papers to sell, a government has votes to win, a charity has donations to acquire¹, and a researcher has a theory at stake. Be aware that conflicts of interest that can influence a study or the report of its findings. Even if the design and method of an intervention study looks good, the researchers may be biased towards showing the method works (whether they are aware of it or not). An obvious bias may exist due to the source of funding. A good way to check bias is to check who funded the research and check where the research is published.

Probably less bias: (green light). If research has been funded independently by the central UK government through one of its research funding Councils; through regional government (e.g. The Welsh Government) or by certain charity research funders¹, then it is less likely to be biased. The research funding has been allocated on a competition basis (not commissioned) and has been rigorously and anonymously reviewed by other scientists. If research is reported in peer reviewed scientific journals it is also less likely to be biased. This means that the methods used in the research have also been checked and reviewed by professional researchers, and the article will only appear in the journal if it's been approved. You can see whether or not a journal is peer reviewed on the front page of the journal or the journal website's home page.

Probably more bias: (red light) be wary of research into any intervention carried out by those who stand to gain by its success, whether financially or in reputation. Research that has been privately funded by a company selling a particular intervention approach, or a charity that devised it, is likely to be biased. Where research is commissioned or undertaken to answer questions of health policy or social policy, check out the background of the research. Regardless of who carried out or paid for the research, beware of any report of findings which aims to score points for a particular political position or personal opinion. Where research findings are used in media reports to make a particular case, check out whether it is really evidence that is being reported or simply opinion and distorted evidence.

3.4 Caution checklist: Reasons for not believing

Remember that whether someone is carrying out either basic science or policy led research, data should always be collected using the highest standard. The data report should also be truthful in relation to the claims that it makes. For example, if the research was exploratory, is this acknowledged? Or on the contrary are the claims too strong (and possibly false) in relation to what the data really show?

Evidence can be distorted. Be sceptical about the evidence you read and hear about. Do not believe the research evidence unless you are reassured by asking these questions...

- Is the study really research? - Does it provide new knowledge that is generalisable and were the hypotheses well documented before the study began?

¹ There are a couple of useful indicators that a charity research funder is likely to have less bias. If the charity is a member of the Association of Medical Research Charities, or is accredited by the National Institute of Health Research, then the research projects it funds are less likely to have bias.

- Is the study well designed? Does it use systematic, rigorous methods and appropriate analysis?
- Are the claims made supported by evidence? Is an exploratory piece of research trying to make a big claim?

Also ask about biases: Is the interpretation of the research biased? Who funded it? Are there vested interests involved?

4.0 What goes on in research – Or, why does research take so long?

People often complain that research takes too long. Who can blame them? On average it can take between two to five years from having a research idea to writing up and publishing the results of a research study. Why do researchers keep people waiting so long for research findings? In this section we briefly outline the rigours of research and describe the scrutiny that research is subjected to before it can be given the 'kite mark' of acceptable research. Hopefully this will help you understand the reasons behind the long delay and you can judge for yourself if it is worth waiting for!

4.1 The research journey

A research study embarks on a long journey which most people never know about (See Figure 2). The journey starts as an idea which is developed as an application for funding after the researcher has exhaustively reviewed all other relevant research using a search engine like PubMed or Web of Knowledge. The application is reviewed anonymously by other researchers in the same field who advise the funders whether it should be funded or not, based on its originality, quality of methodology, feasibility, importance and impact. This review process takes at least 6 months. Only around 15-20% of proposals are funded, which is not a very large success rate (this is one of the reasons behind a lack of good quality autism research). If the funding application is successful, before a project can start, the researchers will need to first obtain Ethics Committee approval and appoint and train research staff, which takes another 3-6 months. Finally data collection begins! Methodology and techniques for the research are prepared and tested, and before the study begins, a pilot study is run. This uses a small group of participants and is intended to determine whether the study is feasible in terms of its methodology. Then recruitment of participants and the data collection phase begins. Strict methods of recruitment and consent of participants are carried out as agreed via the ethics committee. When the data have been collected they must be scored and entered on a database and analysed using statistics to ensure that any effects seen are not just due to chance.

4.2 The rigours of publishing research: peer reviewed journals

When the study is complete, and the results are analysed, there is still more work to do. Getting the results out into the wider research community is known as dissemination and is a requirement for all research. Researchers attend national and international conferences and share their results with academics and with participants and non-academic professionals. This dissemination can typically take place 2 or 3 years after the participants engaged in the research. The study has to be written up in a specific way and researchers identify an academic journal in which they would like to publish their findings.

Before it can be published the research article must go through the peer-review process. This process is very rigorous and it sets and maintains the standards for research. This is a process by two or more scientists working on similar projects that will assess the study and say if they think it is good enough to be published. These reviewers read the study and comment anonymously and critically on any aspect of the study, from selection of participants, to the statistical tests chosen, to the conclusions that have been drawn

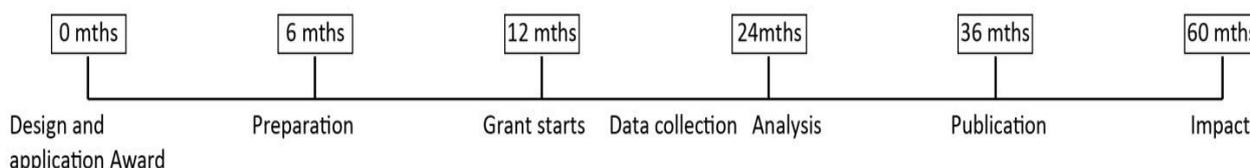
from the results. Researchers carry out peer review of both research articles and grants in their own time in addition to their normal duties. The process can be labour-intensive and demanding but peer-reviewing is part of the professional contribution that researchers make to maintaining standards. Reviewing is usually carried out 'blind' so that the reviewer will not know whose article they are reading. Once the reviews have been returned, the editor asks the researchers to reply to the reviewers' comments and make any necessary changes. This could be as much as running another part of the study or as little as changing the wording in some of it. The editor can also decide to reject the study and not publish it. In reputable journals, in which scientists aim to publish, an acceptance rate of 20% is common. Compare this with posting on the internet!

The purpose of peer-reviewed publication is that the standard of scientific research is maintained. It is anonymous so that a reviewer can feel able to make any comments they see necessary. The editor has the overall say in whether a study is published. Scientists take this process seriously. The downside to this process is that it can take months, if not years, for studies to be published and get into the public or at least the professional domain.



Finally the research article is accepted for publication. The paper goes into press (up to 1 year) and finally emerges as the 'evidence' you read. However this evidence is just part of the research cycle and may provide exploratory evidence on which a more focused study can be built to test a theory. If the findings are strong they should have impact on medical or social policy and practice though the extent of the impact will depend on the success of the dissemination activities and the research-awareness of practitioners and policy makers.

FIGURE 3: A TYPICAL RESEARCH JOURNEY:



Professionals outside of universities often complain that it is hard to get copies of research papers as the journals want payment for them. This situation is changing. Open Access (OA) is an alternative publishing model that enables peer-reviewed articles to be freely available for anyone with access to the Internet to read, rather than limiting readership to subscribers only. It is seen as a way of opening up academic research to everyone to read and use.

In the UK, the research councils, and other funding bodies such as the Wellcome Trust, are requiring the academic researchers to whom they give money for projects to ensure that all outputs from their grants are made open access. They see advantages to society and the economy as a whole of making work visible to all researchers and users of research including those outside academic circles. The Research Councils UK, which is the strategic partnership of the UK's seven Research Councils, says the following on its website: "Free and open access to publicly-funded research offers significant social and economic benefits. The Government, in line with its commitment to transparency and open data, is committed to ensuring that such research should be freely accessible. As major bodies charged with investing public money in research, the Research Councils take very seriously their responsibilities in making the outputs from this research publicly available – not just to other researchers, but also to potential users in business, charitable and public sectors, and to the general public."²



² (<http://www.rcuk.ac.uk/research/Pages/outputs.aspx>, accessed 02-07-2013)

This is currently ongoing and working out the economics of the open access publishing is not without challenge. However, while it may still be difficult to obtain a journal article that you would like to read, it should become easier in the next few years.

There is another route to reading research papers. If you know the name of one of the researchers or authors of a particular article, you can find an email address for them via Google and then can always email them and ask for a reprint. Include the date of the study, the title and publisher if you know these. The author will send you an electronic copy of the article.

4.3 Take home message: Understand the quality control

Each research study completes a long and difficult journey in order to arrive at the standards that are expected by the field. Research is open to scrutiny and criticism throughout its long journey and researchers value this rigorous process in the knowledge that the research evidence that emerges at the other end can generally be trusted. But what about the non-academic user of the research? For the research participant, the non-academic practitioner, the charity funder who has waited years to hear about the results of this research study, is it worth the wait? If the alternative is inaccurate, sketchy data gathering, or incorrect evidence, and cannot be trusted then we argue that it is. But greater transparency about this stringent research process and greater support to speed the different elements of the process should also be a priority.

5.0 Where next?

5.1 Summary: The story so far

Many people who work in the field of ASD need to understand research evidence or gather research evidence.

- Knowing and understanding the research evidence for interventions in ASD improves practice and policy.
- In order to know that an intervention is effective, we need to measure change systematically.
- Formal research is different from evaluation and audit, it is aimed at generating new knowledge and testing hypotheses.
- Basic science research has different methods from policy research but all data should be collected, reported and interpreted using stringent standards.
- Research follows a cycle where previous research findings drive new research.
- Opinion and anecdotes can inform research studies but they are not in themselves research.
- Research can be biased. Research which is funded by a government agency (e.g. NHS, or Research Council) or certain charities, and published in a peer-reviewed journal, is less likely to be biased.
- Research takes a long time. The process of doing research, from having an idea, getting funding, carrying out the study, analysing the results and disseminating the findings can take years. The impact of a finding and the effect it has in the wider world on practice and policy can take even longer.
- Unless we measure and test interventions in a systematic way, using reliable research methods, we cannot make progress in to help children and adults with ASD.

5.2 Want to know more?

If you would like to carry out research yourself and don't have research training or would just like to know more about the tools of the research trade, join us for Part 2 of the ASD Research Toolkit. Part 2 is designed for anyone interesting in learning more about research even if they do not have any research methods training. It provides details about techniques through tools such as; *research design detector*, the *methodology monitor*, the *results reviewer*, and the *conclusion checker*.

Contact us if you are interested in following up with this online course:

Wales Autism Research Centre – email: warc@cardiff.ac.uk

5.3 Resources

The ESRC, NHS and MRC publish guidelines for peer reviewers on their websites:

http://www.esrc.ac.uk/images/Short_version_reviewers_checklist_tcm8-8099.pdf

<http://www.ct-toolkit.ac.uk/routemap/peer-review>

<http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002570>

<http://deevybee.blogspot.co.uk/2012/02/neuroscientific-interventions-for.html>

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Michael Blastland's summer school on statistics on the BBC website

<http://news.bbc.co.uk/1/hi/magazine/7554022.stm>

<http://www.bbc.co.uk/news/magazine-18952037>

Network Autism <http://network.autism.org.uk/>

Sense about Science Website <http://www.senseaboutscience.org/>

Dorothy Bishop Blog <http://deevybee.blogspot.co.uk/>

Medical Research Council website at: www.mrc.ac.uk/index/funding.htm

Early Intervention Foundation on early intervention measures of social problems.

<http://www.earlyinterventionfoundation.org.uk/our-approach/how-the-foundation-can-help>

Alliance for Useful Evidence: on promoting useful evidence in decision making.

<http://www.alliance4usefulevidence.org/tp://www.earlyinterventionfoundation.org.uk>