

This is a repository copy of *Providing psychoeducation after an autism diagnosis: findings from an evidence-based consultation project.*

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/198814/>

Version: Published Version

Monograph:

Beresford, Bryony Anne orcid.org/0000-0003-0716-2902 and Mukherjee, Suzanne Kathleen Mary orcid.org/0000-0002-9012-0369 (2023) *Providing psychoeducation after an autism diagnosis: findings from an evidence-based consultation project.* Research Report. University of York

<https://doi.org/10.15124/yao-myeq-qn63>

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



UNIVERSITY
of York

Providing psychoeducation after an autism diagnosis: findings from an evidence-based consultation project

Bryony Beresford & Suzanne Mukherjee

Title: Developing guidance and recommendations for providing psychoeducation after an autism diagnosis: findings from an evidence-based consultation project

Authors: Bryony Beresford, Suzanne Mukherjee, Social Policy Research Unit, University of York

Date: January 2023

Publisher: University of York

DOI: 10.15124/yao-myeq-qn63

Acknowledgements and disclaimers

This work was commissioned by the Autism Team of NHS England's Learning Disability and Autism Programme. The views expressed in this publication are those of the authors and not necessarily those of the NHS, NIHR, or the Department of Health and Social Care.

Referencing

This report should be referenced as:

Beresford B, Mukherjee S. (2023) Providing psychoeducation after an autism diagnosis: findings from an evidence-based consultation project. York: University of York.

<https://doi.org/10.15124/yao-myeq-qn63>

Table of Contents

Acknowledgements.....	iv
1. Introduction.....	1
2 The project	2
2.1 Project overview.....	2
2.2 Project objectives.....	2
2.3 Project methods.....	2
2.3.1 The consultation work.....	2
2.3.2 Review of existing autism psychoeducation programmes.....	3
2.4 The structure of the report.....	4
3. Experiences and impacts of an autism diagnosis: existing evidence	5
3.1 Understanding the wider context	5
3.2 The experiences of receiving an autism diagnosis	5
3.3 The wider literature on the diagnostic experience	6
3.4 The outcomes of an autism diagnosis.....	7
3.5 Summary.....	7
4. Meeting needs arising from an autism diagnosis.....	9
4.1 The options.....	9
4.2 Psychoeducation programmes.....	9
4.3 Evidence on the impact of psychoeducation programmes	10
4.4. Psychoeducation programmes for autistic adults.....	10
4.4.1 Current autism guidance.....	10
4.4.2 Availability of autism psychoeducation programmes.....	10
4.4.3 Existing psychoeducation programmes for autistic adults.....	11
4.4.4 The impact of autism psychoeducation programmes.....	11
4.6 Summary.....	12
5. Experiences of being diagnosed: what autistic adults taking part in the consultation work told us	13
5.1 Receiving the diagnosis.....	13
5.1.1 The intensity of the emotional response	14
5.1.2 A pre-occupation with “What does this diagnosis mean for me?”	14
5.1.3 Practices affected how people felt about the diagnosis	14
5.2 Needs experienced as a result of the diagnosis	14
5.3 The needs of family members	15
5.4 Summary.....	15
6. Meeting psychoeducation needs: key principles	16
7. The provision of ‘curated’ information resources.....	17
7.1 The need for ‘curated’ information resources	17

7.2 Types of information	18
7.3 The importance of different media	18
7.4 The provision of curated information: recommendations	18
8. Practice prior to the psychoeducation programme	20
8.1 The diagnostic assessment session/s	20
8.1.1 The diagnostic assessment session/s: recommendations.....	20
8.2 The feedback session	21
8.2.1 The feedback session: recommendations.....	22
8.3 The assessment report.....	23
8.3.1 The assessment report: recommendations	23
8.4 The de-brief appointment(s)	23
8.4.1 The de-brief appointment(s): recommendations	24
9. The psychoeducation programme	26
9.1 Views about psychoeducation programmes	26
9.2 Critical features of psychoeducation programmes	28
9.2.1 Autism practitioner and expert by experience involvement	28
9.2.2 Content, structure and approach	29
9.2.3 Group size and make-up	30
9.2.4 Timing.....	31
9.2.5 Venues and time of day.....	31
9.2.6 Mode of delivery.....	31
9.3 Reviewing existing autism psychoeducation programmes	32
9.3.1. Context.....	32
9.3.2. The programmes and their development	33
9.3.2 Findings from the review	33
9.4 Autism psychoeducation programmes: recommendations.....	34
10. Conclusions	36
11. References.....	38

List of figures

Figure 1: The different types of need of newly diagnosed autistic adults	1
Figure 2: Types of information and support need arising from receiving diagnosis	6
Figure 3: Information and support needs arising from the diagnosis	15
Figure 4: Responding to the psychoeducation needs associated with receiving an autism diagnosis: overview of the recommended strategy.....	16
Figure 5: Existing autism psychoeducation programmes: areas of weakness.....	34
Figure 6: Meeting the psychoeducation needs associated with being diagnosed	36

List of tables

Table 1: Numbers consulted and consultation methods.....	3
Table 2: Being given an autism diagnosis: emotional responses.....	13

Acknowledgements

We are very grateful to all those who took part in this project. We know that, for many, taking part required them overcoming multiple demands on their time or a reluctance to join an unfamiliar on-line group meeting. Many shared difficult stories. Thank you all for your commitment and contributions.

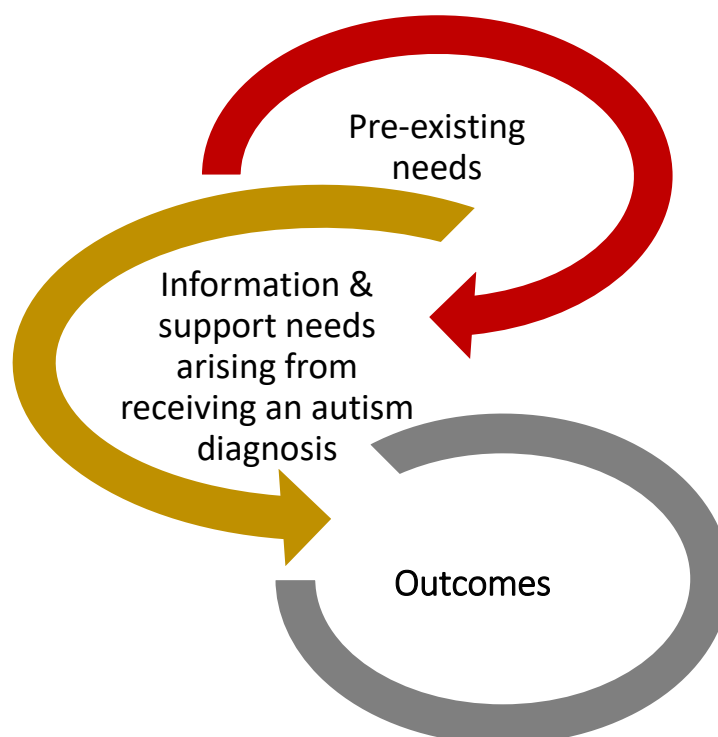
We would also like to thank the organisations and services who assisted by sharing invitations to take part in the project with autistic adults or family members.

1. Introduction

To date, the focus of much of the activity and resource directed at improving the lives and outcomes of autistic people has been to increase access to a timely, high quality diagnosis. As a result, the majority of specialist autism services providing diagnostic assessments are just that: a diagnostic service with no immediate or longer-term post-diagnostic support offered. Thus, mapping work carried out in 2016 identified just 18 localities (i.e. NHS trusts/Local Authorities) in England with an autism-specialist service providing both diagnostic assessment *and* post-diagnostic support.¹ This figure, corroborated by national audits,² represents less than a fifth of localities in England.

This lack of any post-diagnostic provision risks two types of need remaining unmet, and jeopardises positive outcomes being achieved as a result of the autism diagnosis, see Figure 1. First are any pre-existing needs (e.g. mental health, social, independent living etc.). Whilst these might be identified during the assessment process, they will require the initiation of referrals to (often non-autism specialist) services, typically by the GP. Second are the not insignificant information and support needs arising from being diagnosis. The focus of this report is the latter, collectively referred to as **psychoeducation needs**.

Figure 1: The different types of need of newly diagnosed autistic adults



2 The project

2.1 Project overview

This is the report of a project commissioned by NHS England in response to a growing evidence base on the information and support needs people experience when they receive a diagnosis of autism, and the impact of failing to meet these needs. The project was carried out by researchers at the University of York and commissioned by the Autism Team of NHS England's Learning Disability and Autism Programme.

This project focussed on just one element of post-diagnostic support: the information and support needs arising from receiving an autism diagnosis, or psychoeducation needs. This should not be taken to imply that other components of autism-specialist post-diagnostic support are less important or not needed. Current NICE guidelines and national policy and strategy documents make clear recommendations regarding what autism-specialist post-diagnosis support should comprise, and recently published research supports this position.¹

2.2 Project objectives

The overall objective for the project was to develop guidance and recommendations – for NHS England, commissioners and autism practitioners - on meeting the psychoeducation needs of autistic adults arising from receiving an autism diagnosis. It comprised two core components:

- consultation work with autistic adults, family members and practitioners;
- a review of practice and interventions delivered by autism specialist services already commissioned to provide psychoeducation post-diagnosis;

The project was informed by two bodies of evidence:

- the experiences and outcomes of receiving an autism diagnosis;
- the information and support needs which arise as a result of any diagnosis, and interventions designed to meet such needs.

2.3 Project methods

2.3.1 The consultation work

We consulted with autistic adults, autism practitioners, autistic adults working as 'experts by experience' in specialist autism services, and a small number of family members. The principle purpose was to further understand the information and support needs arising from being diagnosed with autism as an adult, and identify the interventions and practices required to meet these needs.

Consultations took place between April and June 2021 via attendance at a focus group or workshop or, where autistic adults were unable to attend a focus group, a one to one conversation with one of the researchers, see Table 1. Invitations to autistic adults to take part in the consultation work were distributed by two diagnostic services, Autistica’s Insight Group, and via the research team’s existing networks. A total of sixty people took part, each attending one consultation event. Services represented were situated across England.

Table 1: Numbers consulted and consultation methods

	Total number consulted	How we consulted
Autistic adults	26	4 x focus groups 2 x 1:1 conversations
Practitioners	25	2 x workshops
Experts by experience	5	
Family members	4	3 x focus group 1 x 1:1 conversations

The autistic adults involved represented different ages and age at diagnosis, different reactions to the diagnosis, and different experiences of post-diagnosis support, including a some who had attended a psychoeducation programme, see Appendix 1 for further details.

Eight autism specialist services were represented in the consultation work. All were commissioned to provide some level of post-diagnostic support, with seven currently delivering psychoeducation programmes^a in the post-diagnosis period.

This consultation work was reviewed and approved by University of York Research Ethics sub-committee: Social Policy and Social Work (Ref: SPSW/S/21/1)

2.3.2 Review of existing autism psychoeducation programmes

Autism specialist services in England with extensive experience of delivering psychoeducation programmes^b were invited to take part in an interview about their programme and practices, and share copies of any intervention materials. Eight of the nine services approached took part. Seven were currently offering a psychoeducation programme^b to newly diagnosed

^a Described more fully in Chapter 4, psychoeducation programmes are manualised interventions delivered over a number of sessions and designed to address information and support needs arising from receiving a diagnosis. The preferred mode of delivery is via groups.

^b Services identified by the research team, primarily through previous national mapping work (Beresford, 2020).

autistic adults on a routine basis. The research team systematically collated this information and then reviewed each programme against findings from the consultation work on what a 'good' psychoeducation programme for autistic adults should look like.

2.4 The structure of the report

Chapters 3 and 4 review existing evidence relevant to meeting the information and support needs which people experience when they receive an autism diagnosis. This makes the case that addressing psychoeducation needs should be the cornerstone to post-diagnostic support, integrated into, and commissioned as part of, the diagnostic pathway.

Chapters 5 to 9 reports the project findings and makes recommendations. Chapter 10 sets out key conclusions and the core principles of ensuring that the information and support needs arising from receiving a diagnosis of autism as an adult are properly met.

3. Experiences and impacts of an autism diagnosis: existing evidence

3.1 Understanding the wider context

In order to understand the information and support needs which arise from receiving an autism diagnosis, it is necessary to understand what people's expectations and experiences may have been in the period leading up to that moment.

First, what people are hoping from the autism diagnostic assessment varies widely. Some are positively looking for an autism diagnosis because it is seen as the means to access the support they need or confirm something they have suspected for a while. However, in instances where others have suggested and initiated the referral, the person may not believe they could be autistic, or want to be diagnosed with autism.^{3, 4 1, 5}

Second, many will have had to wait a considerable period of time for the diagnostic assessment. In the UK, waiting lists are typically many months, if not years.^{5, 6 4} This period of waiting may serve to increase expectations, or hope, that being diagnosed with autism will improve things and open up new sources of support.

Third, the assessment process itself is demanding. It often involves attending a number of different assessment sessions, often spread over a number of weeks.^{1, 7} While many report being satisfied with this process,^{1, 4, 7} it can be challenging. This can be because the diagnostician(s) are insufficiently expert in autism, or the focus is on the negative aspects of the diagnosis, or there is no effort to adapt the physical environment to accommodate sensory sensitivities.⁸ Even those assessed by high quality specialist autism services report that the process is emotionally demanding due to involvement of multiple people and the requirement to recall difficult childhood experiences.¹

Thus people receiving the news that they are autistic are often very different from each other, with some more vulnerable than others.

3.2 The experiences of receiving an autism diagnosis

Studies consistently report that the most common emotion people experience when they are told they have autism is one of relief.^{1, 9-11} There are multiple reasons for this. Diagnosis can offer an explanation of their experiences of life and the difficulties they have had.^{1, 9, 10} It can legitimise how a person feels about themselves and how they behave, and it can allow

people to let go of, or re-frame, past struggles.^{9, 11} Finally, an autism diagnosis is seen as a source of hope: unlocking access to the help they need.¹

That said, it is important to note that, for some, their *immediate* reaction to the news includes, or is entirely, a negative response. Thus studies report feelings of shock, confusion, anxiety, anger, sadness, shame and being overwhelmed.^{1, 4, 10, 12-14}

Critically, and perhaps rarely observed by diagnostic services or other practitioners, initial feelings of relief may be superseded by negative, or mixed, feelings about the diagnosis. People report struggling to make sense and process the diagnosis, and what it means for them. They describe feelings of anxiety, confusion and dismay. There can also be sadness, grief and anger over years which could have taken a different path or been less troubling if they had been diagnosed earlier in life. Anger at others' (e.g. family, health or education professionals) failure to act earlier in seeking an autism diagnosis is another emotional reaction described. Furthermore, a sense of hope generated from being diagnosed can be lost when the lack of post-diagnostic support becomes apparent.^{1, 4, 8, 10, 12, 15-18}

Finally, autistic adults report feeling unsupported as they try to process and deal with the implications and possibilities of an autism diagnosis.^{1, 4, 9} Discovering there is no support to help them with this process is distressing *in itself*, increasing feelings of isolation and having nowhere to turn.¹ We also know that a lack of support can mean the feelings and struggles described above can endure and may also prevent individuals acting to address other needs and situations in their life.¹

3.3 The wider literature on the diagnostic experience

The evidence presented above reveals the range of emotional and informational needs arising from being diagnosed as autistic. These align with those reported across a wide range of diagnoses and summarised in Figure 2.^{19, 20}

Figure 2: Types of information and support need arising from receiving diagnosis

- information and understanding about the condition and, if relevant, its treatment
- understanding emotional responses to the diagnosis
- acquiring self-care and self-management strategies
- advice on sharing the diagnosis with others
- recommendations about trustworthy sources of further information
- information about formal and informal support

Recognising that a diagnosis generates needs for *information* about the condition and living with it, and *support* with processing, coming to terms and acceptance indicates a multi-faceted response is required.

To accept ... and adapt.. a [newly diagnosed] patient must not only receive proper information but also receive emotional support and guidance.¹⁹

It also implies that being diagnosed in itself carries risks because of the needs it may generate, and the potential impacts on individuals if these needs are not met. We therefore turn now to look at what is understood about the outcomes of receiving an autism diagnosis.

3.4 The outcomes of an autism diagnosis

Overall, existing evidence suggests that the outcomes of an autism diagnosis can be highly variable. We know there is potential for a wide range of positive impacts arising from an autism diagnosis. The diagnosis itself can provide people with an explanation for their difficulties, exonerate them from feelings of fault or blame;^{12, 14, 21} mean they no longer feel the need to be neurotypical^{12, 22} and are less constrained around using stimming to reduce anxiety.²³ Greater self-understanding, and situations that can trigger anxiety and distress, can lead to the development of new coping strategies,^{9, 22} as well as greater self-compassion and self-care.¹² Some individuals report beginning to see the unique and desirable qualities of being autistic,²³ and/or improved self-esteem and self-acceptance.^{12, 15, 21} Diagnosis can also enable individuals to access services and support,^{1, 21, 24} including opportunities to meet other autistic people, providing a sense of shared experience and acceptance not found elsewhere.^{14, 15}

However, such positive impacts and experiences are not universal. We know that some people report seeing no value in the diagnosis and struggle accepting it, with significant negative consequences for their mental health.^{1, 9, 12} Experiences of disclosure of diagnosis to others can be highly variable. While it can lead to some being more understanding and positive towards the person diagnosed,^{12, 21} negative reactions are also encountered, including the refusal of others to accept the diagnosis, being scrutinised for autistic traits, being patronised or viewed as disabled, or others not understanding the significance of the diagnosis for them as individuals.^{12, 21, 22} This can lead to a breakdown in relationships, particularly where the person diagnosed seeks to establish a new identity and way of life.¹² Some autistic adults report experiencing discrimination at work following disclosure, sometimes leading to job loss.⁹

3.5 Summary

This chapter began with situating the experience of being diagnosed with autism in the 'backstory' of the circumstances leading up to the referral for diagnostic assessment and the

different feelings and expectations people may have. The emotional demands of a long wait for an assessment, and the assessment process itself, mean some may come to the moment of learning they are autistic from a position of vulnerability.

We then went on to summarise two key bodies of evidence: i) the experiences, and emotional and informational needs, which being diagnosed with autism may generate; ii) the outcomes of an autism diagnosis.

Together existing evidence reveals the complexity of responses and challenges that receiving an autism diagnosis may generate. It also suggests that if people are to positively benefit from an autism diagnosis and, equally important, the risk for negative outcomes is to be minimised, information and support needs arising from that diagnosis have to be addressed. This suggests that investment in diagnostic assessment alone cannot be justified, and that diagnostic services need to have the resources and capacity to respond to and meet psychoeducation needs. The following chapter considers what the evidence tells us this support should look like.

4. Meeting needs arising from an autism diagnosis

4.1 The options

Any clinical or diagnostic team has two broad options with respect to addressing or responding to the information and support (or psychoeducation) needs arising from a diagnosis. Either its response can be partial and reactive,²⁵ and indeed this is the experience of many people across a range of diagnoses.²⁵⁻²⁹ Or its approach can be systematic and holistic. The core pillar to the latter approach are psychoeducation programmes.²⁵ We describe these below and the evidence on their effectiveness. We then go on to consider the evidence regarding their use by autism diagnostic services, and what is known about their impacts.

4.2 Psychoeducation programmes

The overall objectives of psychoeducation programmes are to educate, support acceptance, and empower newly diagnosed people. They are defined as being professionally-led interventions which integrate systematic, structured educational elements about the condition with therapeutic work to support acceptance of the diagnosis (and, if relevant, its treatment), and to equip and develop coping and self-management skills. They span a fixed number of sessions and written materials are typically used to supplement session content.^{30-33,34}

The therapeutic element can be regarded as 'simple', as opposed to complex (which would require expertise in a particular psychological or psychiatric therapeutic technique or qualification).²⁵ Thus, psychoeducation programmes can (and are) delivered by a range of professionals. The key thing is facilitators are expert in the specific condition and its management and have the core communication and interpersonal skills required to deliver the programme. Whilst not prescribed, psychoeducation programmes can be co-facilitated by experts by experience.

Group-delivery is the preferred mode by which to deliver psychoeducation programmes. The rationale for this are the benefits it offers in terms of shared learning, encountering others with similar experiences, and facilitating new social connections which may endure once the programme is completed.^{35, 36}

Self-guided, or self-directed, psychoeducation programmes also exist.³⁷ Whilst developed by professionals, there is no or minimal professional involvement whilst the individual is undertaking the programme.

4.3 Evidence on the impact of psychoeducation programmes

Recent systematic reviews of evidence on the effectiveness of psychoeducation programmes for a range of conditions identify limitations in the current evidence base (e.g. number and quality of studies, heterogeneous outcomes, interventions poorly defined). Despite this, all conclude that existing evidence supports the use of psychoeducation programmes,^{33, 38-40} with improvements in knowledge of the condition, symptom severity, relapse rates, adherence to treatment and psychosocial outcomes reported.

Some studies have explored factors which support intervention effectiveness. A key issue appears to be the capacity to personalise programme content to maximise its relevance and meaningfulness,^{41, 42} something that aligns with wider understanding about effective teaching and information exchange.⁴³ Furthermore, existing evidence does *not* support self-directed, or self-guided, psychoeducation as an alternative to professionally-led psychoeducation programmes.^{44, 45}

4.4. Psychoeducation programmes for autistic adults

4.4.1 Current autism guidance

The NICE guideline⁴⁶ recommends that all adults who have received a diagnosis of autism should be offered a follow-up appointment to “discuss the implications of the diagnosis, any concerns they have about the diagnosis, and any future care and support they may require” (p22). Whilst not presented as having a psychoeducation function, the follow-up appointment has the potential to address information and support needs but only in a very limited way. Aside from this, psychoeducation needs are not acknowledged. This runs counter to the NICE guideline for autism in childhood⁴⁷ (which recommends the offer of a psychoeducation programme to parents) and other diagnostic groups, including common mental health problems.⁴⁸

4.4.2 Availability of autism psychoeducation programmes

Work to map autism specialist services and what they offer carried out in 2016 found that the great majority of diagnostic services are not commissioned to offer a psychoeducation programme as part of their diagnostic pathway.¹ Some services had offered psychoeducation programmes in the past but these were no longer offered, either due to changes in commissioning arrangements or waitlist pressures⁴⁹ meant there was no capacity in the service to deliver such programmes. There is no evidence to suggest any marked change in this situation.

4.4.3 Existing psychoeducation programmes for autistic adults

As noted above, previous mapping work,¹ and subsequent opinion gathering, suggests only a small minority of autism diagnostic services in England offer a psychoeducation programme. Each service has developed its own programme and none have published a manualised version of it, or made it more widely available in some other format. Furthermore, no other descriptions or manuals of autism psychoeducation programmes (from elsewhere in the UK or otherwise) have been published.^c

4.4.4 The impact of autism psychoeducation programmes

Evidence on the impacts of autism psychoeducation programmes is extremely limited. There have been no trials^d and, to date, just one study has published evaluative evidence.¹ This study conducted an exploratory comparison of the experiences and outcomes of people diagnosed by autism diagnostic services but differing in the support they received post-diagnosis. There were two groups:

- ‘Diagnosis Only’ (DO) group: offered a single ‘de-brief’ session after the diagnostic assessment was completed
- ‘Diagnosis & Support’ (D&S) group: offered a multi-session psychoeducation programme (typically group-delivered), with some also receiving a de-brief session beforehand. These services also addressed identified needs, either via in-house interventions or referrals to other services or agencies, with these referrals typically being supported by the service.^e

Interviews with study participants six to nine months after diagnosis revealed that, whilst emotional reactions at the moment of being told the diagnosis were similar for both groups, their accounts of the subsequent months diverged markedly according to whether or not they had attended a psychoeducation programme.

Those who had not attended a psychoeducation programme typically reported unresolved (and sometimes quite significant and pre-occupying) difficulties with respect to understanding and coming to terms with their diagnosis. Some described how they were still actively searching for information and advice and/or that the lack of psychoeducation had

^c A few papers describe post-diagnosis groups for autistic adults (peer or practitioner led) (e.g. Crane et al, 2021; Hatton & Lee, 2021). However, the objectives of the group, facilitators, and/or the content do not align with what is defined as a psychoeducation programme.

^d A team in Sweden report currently trialling a psychoeducation intervention for autistic adults and family members. This comprises four two-hour sessions, with each session described as comprising two, 45 minutes lectures which include pauses and time for questions. Findings have not yet been published. We question the extent to which the intervention truly adheres to the notion of a psychoeducation programme given the strong emphasis on didactic teaching. Furthermore, the rationale for the programme being for autistic adults and family members is unclear and untested.

^e These latter services conformed to the NICE guideline recommended as the type of service which should exist in every locality, referring to them in the guideline as ‘Specialist Autism Teams’.

had a detrimental impact on their mental health. Importantly, some believed the lack of acceptance or resolution around the diagnosis itself was preventing them from attending to other needs and difficulties in their lives.

Such feelings and experiences were not observed among those who had attended a psychoeducation programme. Furthermore, many of these individuals were able to specifically identify why the psychoeducation programme had been helpful to them and the knock-on and wider positive impacts it had on their lives. These included greater self-acceptance, feeling skilled and equipped to manage everyday life, a reduced sense of isolation, and being able to seeing the strengths, or positive side, of being autistic.

Furthermore, an *initial* exploration of differences in outcomes between the DO and D&S group suggest psychoeducation programmes may play a role in determining the outcomes of an autism diagnosis. Thus, evidence of a potential difference in mental health in the immediate post-diagnosis period, with a deterioration observed in the DO group. Furthermore, at 12 months follow-up, statistically significant improvements in mental health, ability to manage everyday life and contacts with autism-specific groups/communities observed in the D&S group were not observed in the DO group.

4.6 Summary

We began this chapter setting out the two possible approaches to responding to the information and support needs arising from any diagnosis. Either the response is partial and reactive, or it is systematic and holistic in the form of a psychoeducation programme. We then defined and described such programmes and summarised wider, and consistently supportive, evidence on their effectiveness.

Focusing then specifically on autism, we noted the virtual absence of a reference of psychoeducation needs in current autism guidance. This, and policy and commissioning emphasis on timely access to diagnostic assessments, likely explains why the majority of autism diagnostic services are not commissioned to provide an psychoeducation programme post-diagnosis. We also reported that no existing psychoeducation programmes have made their intervention manual publicly available, and each service in England delivering such a programme has developed their own 'in-house'. Finally, we described the limited evidence available on the impact of psychoeducation programmes on the experiences and outcomes of adults diagnosed with autism in adulthood.

5. Experiences of being diagnosed: what autistic adults taking part in the consultation work told us

We now move on to report findings from our consultation work with autistic adults, autism practitioners and autistic adults working as experts by experience in specialist autism services. We preclude this, however, with an account of what autistic adults told us of their experiences and responses to being diagnosed, and the needs this generated. It was these stories that grounded deliberations on how services should respond, and what autism psychoeducation programmes should look like.

5.1 Receiving the diagnosis

Among the autistic adults we consulted, their emotional reactions to being told they were autistic replicate and affirm research^f, see Table 2.

Table 2: Being given an autism diagnosis: emotional responses

Relief	<i>It felt like a massive weight was lifted to know there was a reason for my struggles (Autistic Adult, ID 51)</i>
Elation	<i>It felt freeing. It felt like I had the freedom to take away my self-blame. (Autistic Adult, ID 43)</i>
Closure, new sense of identity	<i>It felt right. It was who I was (Autistic Adult, ID 45)</i>
Hope	<i>I had a glimmer of hope that things might be better (Autistic Adult, ID 21)</i>
Confusion about diagnosis	<i>What does it mean? Why have you put me under this bracket? (Autistic Adult, ID 43)</i>
Confusion about self	<i>After I got the piece of paper with the diagnosis and read it I almost didn't know who I was anymore (Autistic Adult, ID 34)</i>
Shame	<i>I remember being ashamed of it, even though I had an answer and it made sense, and I could talk about it with some people, I felt ashamed about it and kept quiet about it for many years. (Autistic Adult, ID 34)</i>
Grief	<i>I started wishing things has been different. If I'd found out earlier.... and that was a very strong feeling that I had nowhere to take (Autistic Adult, ID 25)</i>

^f Summarised in Chapter 3.

However, as well as further confirming existing evidence, their accounts also brought three important new insights:

- the intensity of the emotional response
- a pre-occupation with “What does this diagnosis mean for me?”
- practices during the assessment and feedback session affected how people felt about the diagnosis.

5.1.1 The intensity of the emotional response

First, and not so apparent in the research literature, was the intensity, and sometimes overwhelming nature, of the emotions experienced immediately following diagnosis, as illustrated by the following extract:

When I was diagnosed it was a bit like PTSD, I suddenly remembered things I hadn't before, it was like twenty thousand light bulbs being turned on at once, and I couldn't access any support. I went to mental health services, I went to my GP, and I couldn't get any help. I had to send my son away to spend Christmas with his Dad and I spent it by myself. It took about 6 weeks to process everything and I really needed helping during that time (Autistic Adult, ID 23)

5.1.2 A pre-occupation with “What does this diagnosis mean for me?”

The majority of autistic adults we consulted with described feelings of dis-orientation and uncertainty, particularly in terms of what being diagnosed meant for them and their lives going forward. Indeed, for many, questions such as these dominated their thoughts.

5.1.3 Practices affected how people felt about the diagnosis

Many also believed the nature of the assessment and feedback process contributed to how they felt about being diagnosed as autistic.[§] They described how an assessment which focussed on their difficulties made it hard to see the positives of an autism diagnosis and undermined feelings of self-worth.

You have to go through this process where they are telling you your deficits, it's essentially a very negative process, so they're telling you why you're failing at being neurotypical and then they say 'Ok, that's why' and then that's it. It's upsetting (Autistic Adult, ID 42)

5.2 Needs experienced as a result of the diagnosis

In line with existing evidence, the autistic adults described a wide range of needs associated with the diagnosis, see Figure 3.

[§] We note this has also been reported by Crane 2018.

Figure 3: Information and support needs arising from the diagnosis

- Help with understanding why I have been diagnosed as autistic
- Support with my emotional response to the diagnosis
- Support with accepting diagnosis
- Factual information about autism
- Understanding how autism impacts on me and what it means for my life
- Advice on disclosure of diagnosis to others
- Guidance with sourcing trustworthy information on how to live with autism
- Advice on entitlements, reasonable adjustments, and advocating for self
- Information and advice about connecting with other autistic people

The diagnosis highlighted my difficulties but it didn't give me solutions. (Autistic Adult ID 41)

It's not just about what you want to know. It's also about what you need to know. (Autistic Adult, ID 12)

5.3 The needs of family members

Whilst not the focus of this project, and not explicitly explored during our consultation work, the psychoeducation needs of family members arising from an autism diagnosis was raised by some autistic adults. There is insufficient data on this for us to report on this and we would recommend a specific piece of work is carried out to investigate this issue further.

5.4 Summary

This chapter summarises the diagnosis experiences of autistic adults who took part in this project. They align with the wider evidence, but added further insights. In particular, they demonstrate the intensity of negative emotions which may be experienced on learning of an autism diagnosis, and how these emotions, and the questions the diagnosis raises, can be overwhelming. They also reveal that practices during the assessment process can affect how someone will feel about the news of an autism diagnosis. Finally, they confirmed the wide range of information and support needs such news generates.

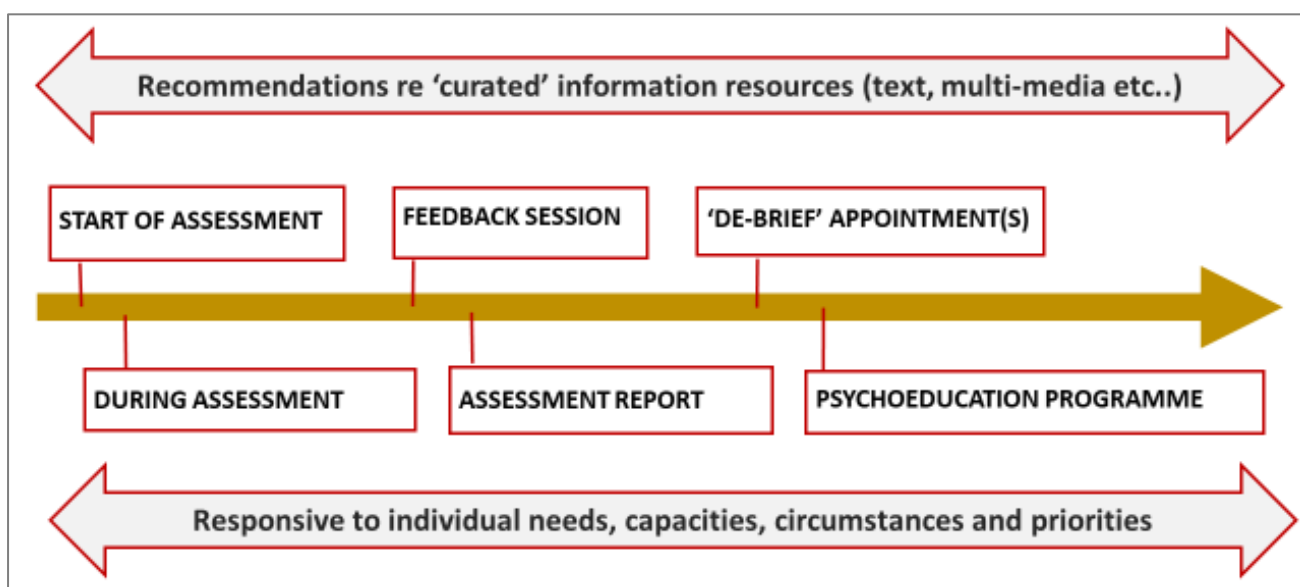
With this in mind, we now move on to report findings from our consultation work on how can services best meet the psychoeducation needs of newly diagnosed autistic adults. Chapter 6 sets out the key overarching message from this consultation work with subsequent chapters considering in more detail the different things that need to be in place to ensure these needs are met.

6. Meeting psychoeducation needs: key principles

There was strong and universal consensus among those we consulted that autism-specialist services providing diagnostic assessments should also provide post-diagnosis support which addresses psychoeducation needs associated with receiving an autism diagnosis. (They also stressed that this is not the only type of autism-specialist post-diagnostic support which needs to be available. In line with existing evidence and clinical guidance,⁴⁶ they also called for support with respect to presenting health, social and other needs, delivered by autism specialists. However, these other aspects of post-diagnostic support are outside the remit of this project.)

Those consulted were clear that responding to the psychoeducation needs arising from receiving an autism diagnosis requires a multi-faceted approach. Figure 4 sets out the points in the diagnostic pathway when attention needs to be paid to psychoeducation and the types of intervention required. The figure also makes clear the need for flexibility, resource and capacity to individualise psychoeducation. This is particularly with respect to the timing of when key interventions are offered and the ability to offer, when required or indicated, the psychoeducation programme via one-to-one sessions as opposed to group-delivery.

Figure 4: Responding to the psychoeducation needs associated with receiving an autism diagnosis: overview of the recommended strategy



Subsequent chapters consider each of the elements set out in Figure 4, summarising consultation findings and our recommendations. Given the provision of curated information resources should occur at multiple points, we consider this first (Chapter 7). Chapter 8 consider practice and interventions *prior* to the psychoeducation programme, and Chapter 9 focuses on the psychoeducation programme itself.

7. The provision of ‘curated’ information resources

A key findings from our consultation work is that, as well as directly addressing psychoeducation needs, services must also support individuals to access additional sources of information. Autistic adults and autism practitioners identified multiple points at which directing to, or recommending, additional information should be considered (e.g. feedback session, assessment report, de-brief appointment(s), during the psychoeducation programme). Critically there was strong consensus that additional sources of information should be salient, high quality and up-to-date. The following sections discuss these issues in more detail.

7.1 The need for ‘curated’ information resources

The autistic adults we consulted highlighted the risks associated with individuals independently seeking out information about autism, particularly in the time immediately following diagnosis. This was both because of the preponderance of false or out of date information available (both print and on-line), and the risk of being exposed to unhelpful views and perspectives.

[Services] need to be clued up enough to point people in the right direction before they go off and do their own thing and bump into these obscure websites and forums and people spreading misinformation. (Autistic Adult, ID 11)

I went down a rabbit hole looking for information. Some of what I found was not helpful. A lot was targeted at parents. I found it belittling and very hard to hear parents talk about how difficult they found their kids. There are also branches of autistic groups which take positions that can be detrimental to you. Not good if you come across it and aren't good at critical thinking (Autistic Adult, ID 42)

Some of the books I found were terrible, so I had to work out myself what was good (Autistic Adult, ID 41)

The only place I would recommend people to go as a site that is autism led and put voices first. There are too many so-called autism websites out there which are actually run by people who don't have autism. (Autistic Adult, ID 17)

It is very important, therefore, that newly diagnosed autistic adults have access to ‘curated’⁵⁰ information resources. The use of the word ‘curated’ is deliberate, implying that recommended sources of information should have been carefully selected and scrutinised by experts by experience and practitioners. This will ensure additional information provided by

diagnostic services is safe, comprehensive and meaningful. Furthermore, the collection should be regularly reviewed and updated.

The issue with recommending services is they may be good today, but they may not be tomorrow. And you need to be very careful with websites...things like fake cures
(Autistic Adult, ID 17)

7.2 Types of information

Autistic adults and autism practitioners identified three types of information relevant to addressing psychoeducation needs: ‘factual’ information about autism, information about formal and informal sources of support (local and national), and information about living with autism. The latter was regarded as critical to supporting acceptance and adjusting to their diagnosis. ‘Living with autism’ information resources which had proved most helpful to the autistic adults we consulted were ‘my life story/lived experience’ type material and ‘hints and tips’ on living with autism authored by autistic adults.

I researched but the most useful thing was watching TED talks that dealt with how people deal with it on a daily basis. (Autistic Adult, ID 31)

It’s the how to manage situations that I didn’t know and that’s harder to find. You can only get this from other people on the spectrum. (Autistic Adult, ID 32)

I didn’t need the counselling, I need a more pragmatic intervention. I needed somebody to say you know you can apply for these things, you can apply for this, this is how you self-advocate for yourself when you go into hospital. (Autistic Adult, ID 15)

7.3 The importance of different media

Finally, the autistic adults we consulted were clear that any collection of information resources has to include materials of different media – on-line only and print, audio and audio-visual, and text and pictorial formats (e.g. comic book).

7.4 The provision of curated information: recommendations

- Diagnostic services should have available a curated collection of sources of information which can be recommended to newly diagnosed autistic adults. The collection needs to include information resources on living with autism, factual information about autism, and information about local/regional/national support organisations and services. It should include different media or formats, with experts by experience closely involved in the resource content and its ‘look and feel’.

- We note that some components of such a resource would be generic; that is, not requiring local adaptation. There may be efficiencies, therefore, in collaborating with other diagnostic services and/or partnering with autism organisations already acting as information providers to create and maintain some of the information resources offered.

8. Practice prior to the psychoeducation programme

8.1 The diagnostic assessment session/s

Undergoing an autism diagnostic assessment will be a new experience for most people. It therefore generates its own information needs. Importantly, findings from our consultation work indicate that whether and how these information needs are addressed can influence responses to, and acceptance of, the diagnosis, and readiness for, and engagement with, a psychoeducation programme.

8.1.1 The diagnostic assessment session/s: recommendations

- At an early stage in the diagnostic assessment process there should be a discussion with the individual about the different ways people respond to hearing the outcome of the assessment process. Clinicians should normalise these different emotional reactions.
- Where possible, and without compromising the assessment process, the clinician should explain the reason, or purpose, for each element of the diagnostic assessment. They should reassure individuals that fuller explanations will be provided at the feedback session.
- Throughout, the language used should refer to difference rather than deficit. The person's strengths and achievement should be noted, whilst acknowledging past or current difficulties.
- Basic information about the psychoeducational support the service would offer if an autism diagnosis was made should be provided (e.g. de-brief appointment; psychoeducation programme). This should be done in such a way as to ensure that the individual does not infer an autism diagnosis is likely, nor to increase disappointment about the lack of support if autism is not diagnosed. It may be helpful to offer a brief explanation of autism-friendly/autism-specific accommodations in the way the psychoeducation programme is delivered.
- Practitioners should use the assessment sessions to form an initial judgement on whether one-to-one delivery of psychoeducation programme may be required, either because of the individual's needs, or because of potential impacts on group dynamics or others attending the group.

8.2 The feedback session

There was strong consensus that the outcome of the diagnostic assessment should be shared with the individual in a face to face meeting.

They just emailed it to me and that was it. (Autistic Adults, ID 32)

[It is important that we] can bear witness to the reaction and validate experiences.
(Practitioner ID 20)

Furthermore, the way the feedback session is managed can strongly influence how an individual reacts and responds to the news of the diagnosis. Three issues are at play. First, the way the decision-making leading to the diagnosis is explained. Second, how the diagnosis is presented; that is, either in terms of deficits or differences. Third, the extent to which emotional responses are attended to.

All the information I got was all very generic and not how it related to me....It didn't go through this is what we found and this is why have decided to diagnose you as autistic and so I didn't help me to process it. (Autistic Adult, ID 15)

Finally, advice related to disclosure must be provided. This was something that practitioners we consulted had not typically considered or routinely integrated into their practice apart from, perhaps, advising on informing employers. However, it was something that autistic adults regarded as crucial. Some deeply regretted who they had shared news of their diagnosis with, or how they shared it. In some cases, the negative consequences of this were significant.

... there was an issue with safety for me after diagnosis as I told everyone, including people that didn't need to know. I could have done with some support straight after with knowing how to step out into the world... how to step out of this room. I learnt a bit too late that you don't need to tell anyone, or maybe [just] to a few people.
(Autistic Adult, ID 26)

I found that I shared too much [on social media]. [You] pour your heart out and then it comes back at you, because people quickly judge you and if they don't really understand autism they can assume that you are incapable of doing certain things.
(Autistic Adult, ID 45)

8.2.1 The feedback session: recommendations

- The feedback session should be a face-to-face.
- It should include a clear explanation about how the team has come to the decision to diagnose autism, including the role played by the different components of the assessment process in coming to that decision. Any conflicts with existing understandings of autism should be identified and explored.
- Throughout, the language used should refer to difference rather than deficit. The person's strengths and achievement should be noted, whilst acknowledging past or current difficulties.
- Individuals should be asked about their feelings about the diagnosis and emotional reactions should be normalised. Individuals should also be advised that their feelings about the diagnosis may change over time, and that is normal.
- The session must include offering advice and discussing plans for disclosure. This should cover all relevant groups/settings (e.g work, family, social networks), including social media.
- It should also include the offer, if the individual wishes, to notify their GP and any NHS or LA social care services which they are currently using.
- The purpose of the assessment report(s) the individual will receive must be explained.
- Other elements of the post-diagnosis offer (e.g. de-brief appointment(s), psychoeducation programme) should be explained. To support take-up, clinicians should specifically identify components of these interventions which will address the individual's particular need or situation.
- In discussing the psychoeducation programme, care should be taken to: i) explain why group-delivery is favoured (i.e. peer learning and support, opportunities to create/extend social networks); ii) recognise the challenges of attending a group; and iii) explain the autism-friendly/autism-specific accommodations in place to support attendance. Written and/or audio-visual (i.e. video) information should also be provided. This should cover programme content, photographs of facilitators and venue, and travel options.
- Details of selected 'curated' information sources should be shared (*see Chapter 7*).

8.3 The assessment report

All the teams involved in this consultation work provided individuals with a detailed written account of the assessment and the conclusions drawn. From their perspective, the main purpose of this was the individual to use to make the case for adjustments or accommodations. For this reason, reports took a particular tone and emphasis, detailing deficits and struggles. However, they recognised this created a tension in terms of the report also being a positive and empowering document for the individual.

In contrast, the autistic adults we consulted with believed they were the primary audience for the assessment report. They found the negative wording dispiriting and discouraging and could undermine positive rhetoric and vocabulary used by practitioners during the assessment and feedback sessions. Furthermore, the physical nature of the assessment report increased the likelihood of individuals dwelling on its contents.

When I got my letter it highlighted all the negative and none of the positives and it felt difficult to be left with that.....

(Autistic Adult, ID 25)

8.3.1 The assessment report: recommendations

- The assessment report must have a covering letter, or explanatory front page, which clearly states the report's purpose and intended audience(s).
- Whilst the individual is not typically the primary audience for such reports, clinical teams should take account of the fact that reports will be read by them, and take care to avoid language or tone which is negative or overly technical.
- Teams should consider incorporating a detachable section summarising the individual's strengths, or present this in a separate document.
- Teams should consider whether details of selected 'curated' information sources should be shared (*see Chapter 7*) alongside the assessment report.

8.4 The de-brief appointment(s)

The autistic adults and practitioners we consulted believed that everyone diagnosed with autism should be offered at least one 'de-brief appointment' in the period immediately following the diagnosis, but also with the option to delay. They believed this would address three key needs during that time: to address questions about the diagnosis itself (including the connection between the assessment process and decision reached), to explore emotional reactions and feelings about the diagnosis, and to support sense-making. There was

consensus that these appointments should be with the/a clinician involved in the diagnostic assessment.

It's really important that as soon as possible after the diagnosis there is a chance to sit down with somebody to discuss it, how you are feeling about it, and how you can move on from that point. (Autistic Adult, ID 11)

Practitioners taking part in the consultation work agreed; however, only a couple of services taking part in this project were commissioned to do so. They noted that individuals can be quite overwhelmed at the feedback session and needed time to process what has happened, after which a de-brief appointment would be extremely valuable. Services commissioned to provide a de-brief appointment believed they addressed needs which could not be responded to within the group psychoeducation format. Practitioners also believed they supported take-up and readiness for the psychoeducation programme, and ensured that maximum benefit was gained from the programme.

When a person comes [to a group] not knowing anything it tends to mean they have a lot of questions and the group can end up being about one or two people because they need that information, and they often stay behind afterwards because they have a lot of things they need to discuss, so for me I think going straight into a group isn't a good idea. (Practitioner ID 12)

8.4.1 The de-brief appointment(s): recommendations

- Individuals should be offered at least one de-brief appointment with a member of diagnostic team. The purposes of such appointments are: to explore and discuss feelings about the diagnosis and emotional reactions to it, to support with making sense of the diagnosis, and to respond to questions about the diagnostic process or diagnosis itself.
- An appointment within 4 weeks of the feedback session should be offered, but with the option to request to delay. Where this occurs, clinics must undertake to pro-actively contact individuals to re-schedule the appointment.
- Judgement about the number of appointments needed should be made on an individual basis.
- Throughout the appointment, the language used should refer to difference rather than deficit. The person's strengths and achievement should be noted, whilst acknowledging past or current difficulties.

- The appointment should check on experiences of disclosure and discussions and advice on managing any future disclosures.
- Details of selected 'curated' information resources (*see Chapter 7*) should be provided.
- The individual should be reminded about the psychoeducation programme. Care should be taken to: i) explain why group-delivery is favoured (i.e. peer learning and support, opportunities to create/extend social networks); ii) recognise the challenges of attending a group; and iii) explain the autism-friendly/autism-specific accommodations in place to support attendance. Written and/or audio-visual (i.e. video) information should also be provided. This should cover programme content, photographs of facilitators and venue, and travel options.
- At the end of the appointment (or at the final appointment), it should be explained how the service will stay in touch (and, if relevant, the support the service can offer) in the period until the psychoeducation programme commences.

9. The psychoeducation programme

This chapter focuses on psychoeducation programmes and their role in meeting the information and support needs arising from receiving an autism diagnosis. (See Chapter 4, sections 4.2 and 4.3 for an overview of such programmes and evidence on their effectiveness.)

We report findings from our consultation work on views about psychoeducation programmes, including issues arising from the fact that these are typically group-delivered interventions. We then go on to consider features of the intervention and its delivery which, those we consulted believed, impact the quality and benefit of the programme. We then report on our review of existing autism psychoeducation programmes against these criteria. Finally, we make recommendations on the steps required to ensure psychoeducation programmes can become routinely integrated within autism diagnosis pathways.

9.1 Views about psychoeducation programmes

Overall, the notion that every adult diagnosed with autism should be offered a psychoeducation programme was supported by those we consulted. An underlying theory of psychoeducation programmes is that peer-learning and the opportunity to hear and share experiences are an important educational and therapeutic components (see Chapter 4). As a result group delivery is the preferred and dominant mode. However, given feelings and concerns which attending or being in groups can engender for autistic people, group delivery was something we discussed extensively with those consulted. There was a range of views and opinions.

Those who had attended a group-delivered autism psychoeducation programme highlighted the importance and value of group delivery, with a range of particular benefits identified including: the opportunity to learn and share strategies from others living with autism; feeling understood and a sense of belonging; being in a social situation without feeling the need to mask; and validation from the group supporting self-acceptance.

The internet is great for information but not for feeling less lonely. I can be myself with the [psychoeducation group]. It helped me to accept that being myself is OK. (Autistic Adult, ID 21)

The biggest thing I got from the group was meeting others who share the same culture because it's just in them; so I've been trying to fit into other people's culture, and it turns out there is a culture of my own. (Autistic Adult, ID 43)

...there's been a massive positive shift in my mental health. ...it's the bouncing ideas and thoughts off people, getting a different perspective, validation from group members. [The group means] I accept myself more. (Autistic Adult, ID 51)

Among those not offered a group psychoeducation programme, there were some who believed this would have been valuable and they would have welcomed this opportunity.

That would have been really helpful, to have prevented future stress. I would have found it really, really helpful to have met people in the same boat. (Autistic Adult, ID 14)

Others, however, were ambivalent about, or opposed to, group-delivered interventions. There was mistrust or scepticism that they could be better than individual sessions. Some regarded group interventions as 'cost-cutting' measures, which de-valued them and their needs. The belief that groups could respond to individual needs and priorities was also expressed. Finally, they highlighted that anxieties and concerns about being in a group could be considerable, and therefore questioned the suitability of group-delivered interventions for autistic people.

I would feel fobbed off. If you go on to any NHS mental health web site at the moment you are offered group sessions on zoom and it feels like it's just a cheap way to offer it.it's not tailored to me, it's quite general, it would work for some people, it would piss me off. (Autistic Adult, ID15)

...[we] should not to be shoe horned into groups when, because of our range of needs and innate difficulties, groups are just difficult and so stressful. (Autistic Adult, ID 23)

I absolutely hate anything in a group..... I hate things where the only thing we have common is that we are autistic I know from talking to my autistic friends that they are absolutely pissed off with being offered things in a group, they just didn't want it, people will react very violently against it, particularly if that the only thing they are offered. (Autistic Adult, ID 15)

Autism practitioners' also shared their observations of the value of group delivery and believed that it offered benefits over and above those gained from receiving a psychoeducation programme via one-to-one sessions. It was for this reason that they chose to deliver their psychoeducation programmes by groups (with some also having the option, where required, to offer one-to-one delivery). They ascribed observed positive impacts on self-confidence and mood to group delivery. At the same time, they also agreed that group-delivered psychoeducation programmes will not be suitable or beneficial for everyone and that the option to deliver via one to one sessions should be available.

These findings carry two key implications. First, diagnostic services should have the capacity and resources to be able to deliver the programme via one-to-one sessions where attending a group programme is not possible or advisable. (We note here that evidence does not support self-directed psychoeducation (*see Chapter 4*).) Second, diagnostic services need to respond to and address the perceptions and concerns that at least some individuals will have about group-delivered interventions. This means the way diagnostic teams present the psychoeducation programme to individuals on the diagnostic pathway needs to be carefully planned so that these concerns and perceptions are consistently addressed. It also means that proper attention is paid to sensory, psychosocial and practical issues which may act as barriers to take-up and attendance.

9.2 Critical features of psychoeducation programmes

This section reports consultees' views on the features of psychoeducation programmes which they believed determined take-up, access, outcomes and experiences of such programmes. We refer to these as the critical features of autism psychoeducation programmes. They include:

- autism practitioner and expert by experience involvement
- the content, structure and approach
- group size and make-up
- timing
- venues and time of day
- mode of delivery

9.2.1 Autism practitioner and expert by experience involvement

In terms of both designing and delivering psychoeducation programmes, there was general consensus that autistic adults and autism practitioners have key and different roles to play in the development and delivery of psychoeducation programmes. Furthermore, their roles are of equal importance.

The knowledge, skills and experience brought by autism practitioners (and identified across all the different groups we consulted) included: authoritative scientific knowledge about autism, extensive experience of the different ways autism can be manifested, and specific, specialist professional expertise in supporting autistic adults (e.g. clinical psychology, social work, occupational and speech and language therapies). In addition, their professional training equipped them to identify or manage disclosure of risk or the need for additional support and meant they were highly experienced in facilitating groups.

Autistic adults, acting as experts by experience (or peer mentors), were consistently identified as making two key and unique contributions as co-facilitators: authenticity and connection.

It's not necessarily in the content of what is being delivered but in the authenticity of the knowledge, and knowing how to redirect people, and knowing that somebody actually identifies with the issue, and a feeling of trust that you are not being perceived as other. (Autistic Adult, ID 25)

Autistic people need to be part of the support process. No one autistic people can represent that experiences of everyone with autism but it's better than someone with no experience at all. (Autistic Adult, ID 16)

Among the services involved in this project, the overall narrative was of increasing involvement of autistic adults in reviewing and revising programmes and in their delivery. However, not all used experts by experience as co-facilitators and the terms under which co-facilitators were contracted, or employed, to work with services was variable, as was the quality of support and supervision. It was emphasised that experts by experience must be properly trained and supported (e.g. de-briefs and supervision and receive appropriate rates of pay).

9.2.2 Content, structure and approach

The core content and structure of psychoeducation programmes is broadly the same across all diagnoses, with the objective of attending both to educational and therapeutic (e.g. supporting acceptance, equipping and empowering) needs.²⁵ Topics emerging from discussions about what should constitute the core content of an autism psychoeducation programme were as follows:

- factual information about autism (e.g. diagnostic criteria; neurodiversity)
- understanding and identifying how autism impacts me as an individual, and what it means for my life
- sharing and exploring emotional responses to the diagnosis
- learning self-management skills, particularly managing anxiety, disclosure, self-care, self-advocacy, and sourcing trustworthy information
- information and advice on rights and entitlements
- supporting connections with other autistic people, including other group members.

There was clear and strong consensus that didactic teaching should be kept minimal, or not used at all. The use of lived experience materials (e.g. short films) alongside factual was strongly endorsed.

Some services noted that they had revised their programmes to decrease the ‘taught content’, and increase time allocated to interactive learning and the therapeutic elements of the programme. This also allowed greater personalisation of the programme content to reflect and respond to the characteristics, needs and concerns of group members, something identified as important by the autistic adults we consulted. The exception to this was the first session where less group work was used in order to allow individuals time to get used to the group format.

Hard copies of teaching materials (e.g. Powerpoint slides) was strongly endorsed, and services using ‘workbooks’ (containing teaching materials as well as space for notes and recording individual responses to reflective activities etc.) reported they were well-received. During our consultation work we heard a range of views on how an autism diagnosis should be presented. Some autistic adults believed programmes should present being diagnosed as a highly positive event, others did not agree. Practitioners and experts by experience were unanimous that a more neutral stance was required in order to hold the group together and ensure no one felt disenfranchised. This was because individuals attending may have very different feelings about their diagnosis or be at different points in the process of accepting it.

9.2.3 Group size and make-up

The services involved in this project adopted different approaches to maximum group size, with this ranging from eight to twelve. The autistic adults we consulted consistently favoured smaller sized groups.

There was 15 in my group and it was too much. Negotiating turn taking was difficult, stressful. (Autistic Adult, ID 33)

Those running psychoeducation programmes and autistic adults believed the value and benefit gained from group-delivered psychoeducation programmes may be affected if an individual’s age, gender or sexuality are different to the majority of those attending a group. Services noted the tension between offering the psychoeducation programme in a timely way and waiting until there were sufficient number to, for example, offer the option of attending a women-only group, or groups according to people’s age.

From my perspective group work would be better with not so much of a mix of ages. For example, one session was on relationships and the lads were laughing about it, giggling and one was talking about Tinder and they thought it was great fun, and I just thought I’m wasting my time here. (Autistic Adult, ID 32)

9.2.4 Timing

There was strong consensus that the timing of when people are ready to engage with, and will get most benefit from, a psychoeducation programme will vary between individuals. There was also agreement that allowing sufficient time before the programme for processing the news and implications of the diagnosis was very important, as was the opportunity to attend one or more de-brief appointments.

Unless you have suspected from some time and it's the final stage of the journey, it can take you to thinking about things you have never thought about before. So then to ask what information or help do you need, the person might not know, they might need some time to accept it. I think offering [psychoeducation] straight away might not be the best way forward, it needs to be flexible for the individual. (Autistic Adult, ID 27)

I do think you need some time to process it. (Autistic Adult, ID 12)

For services, the numbers of people being diagnosed (including, sometimes, their geographical location) determines the frequency at which programmes are delivered. Certainly, individuals should be aware of the likely wait time for the programme. Equally important is that where an individual turns down the first opportunity to attend the programme, the offer to attend a future delivery of the programme should be made at least once more.

9.2.5 Venues and time of day

Services were aware that only running the programme during the day risked excluding those with work or who had other day-time commitments. Autistic adults stressed the importance of offering day-time and evening deliveries. They also urged services to use venues easily accessible by public transport and which could accommodate potential sensory needs. They noted that programmes did not need to be run in the service's main premises. Familiar spaces in community settings were favoured: an approach successfully adopted by a number of services involved in this project.

9.2.6 Mode of delivery

The COVID pandemic caused services involved in this project to implement on-line delivery of their psychoeducation programmes. Although experiences of delivering and receiving psychoeducation in this mode were still very limited at the time of this project, autistic adults and practitioners who had experienced this mode of delivery were able to identify its benefits and disadvantages.

Online groups were seen as minimising strain and emotional demands on participants (e.g. being able to participate from home, 'chat' and 'hands up' functions made it easier to contribute to discussions). Some believed they would not have attended a face-to-face delivery of the programme.

....in your own surroundings, where you have the opportunity to mute yourself if you want, feels like a more comfortable way to be able to contribute to these things, so I'd love for it to continue online and not to be phased out when things go back to normal.
(Autistic Adult, ID 45)

I'm probably more comfortable online, my anxiety is less sitting at home with a weighted blanket in my environment, so I'd rather get to know somebody that way when I'm having to suddenly meet people I don't know. (Autistic Adult, ID 42)

Overall, however, there was caution and concern about on-line delivery. This was located primarily around experiences of lower, or 'skewed', take-up and a reduced likelihood that on-going connections between group members will be formed. In addition, the lack of informal gathering times before, during and after a session precluded informal one-to-one conversations between an autistic adult and facilitator. For autistic adults, these were valued as opportunities to follow-up an issue discussed during the session. Facilitators believed this lack of one-to-one contact meant there was an increased likelihood for unmet needs post-intervention.

A potential third option, for which there was some support among practitioners and autistic adults, was a hybrid model whereby the group starts by meeting on-line and then moves to face-to-face sessions part way through the programme.

9.3 Reviewing existing autism psychoeducation programmes

One of the core objectives of this project^h was to review existing autism psychoeducation programmes. The main purpose of this was to see if any, judged against our consultation work and existing evidence, could be regarded as 'model' programmes which NHS England could recommend for use.

9.3.1. Context

It is important to offer some context to this review. All the services represented in this project reported sustained and high levels of pressure on their services. They noted that commissioning arrangements meant they had to direct greatest attention and resource to providing diagnostic assessments, with increasing referral rates adding additional pressures. A number reported that this compromised capacity for and investment in their

^h See Chapter 2, Section 2.3.2.

psychoeducation programmes. They also questioned the ethics of diagnosing without having the resource to meet information and support needs which may arise from that diagnosis.

9.3.2. The programmes and their development

All the programmes we reviewed were unique and developed ‘in-house’ though some integrated elements of existing autism self-management interventions. The topics covered were similar: unsurprising given they were all psychoeducation programmes. When asked about what would be required to manualise the programme to make it suitable for other services to use, some reported this would take little work, others felt this would be a more substantive task. None had been subject to independent evaluation.

Across all programmes, feedback from attendees and on-going review and reflection within the team meant that programmes structure and materials had been revised (often multiple times) in the period since their original development. Thus there was a strong sense of an on-going learning process about the content, structure and practice of delivering psychoeducation programmes. Practitioners taking part in our consultation work also noted the absence of practice networks concerned with psychoeducation post-diagnosis which hampered sharing of learning across services, contrasting this with well-established diagnostic practice networks. This was seen as a missed opportunity.

We work in these sealed units, vacuums, doing our own things. Diagnostic assessment networks are better, they have more standardised practice. (Practitioner, Workshop 2)

Most reported that, at least in recent years, experts by experience had been involved to some degree in reviewing and re-writing programmes and/or were now co-facilitating programme delivery.

9.3.2 Findings from the review

We reviewed the content, structure and delivery of each of these programmes against the findings of our consultation work, and existing evidence on factors affecting the effectiveness of psychoeducation programmes. All fulfilled many of the key features of an autism psychoeducation programme identified through our consultation work. However, each had areas of weakness and none had been subject to robust evaluation (*see Figure 5, overleaf*). As a result, none, in their current form, can be presented as a ‘model’ autism psychoeducation programme which can be recommended to diagnostic services. We stress, we are not saying these programmes do not offer great benefit and are highly valued. Indeed, the development of a ‘model’ psychoeducation programme should build on and incorporate elements and practices observed in existing programmes.

Figure 5: Existing autism psychoeducation programmes: areas of weakness

Experts by experience not involved, or not sufficiently involved, in programme development and delivery.

Clinical content risks engendering a deficit rhetoric and precludes exploration of what autism means to, and is experienced by, individuals.

Lack of multi-disciplinary representation among programme facilitators (i.e. predominantly clinical psychology) reduces holistic approach and breadth of knowledge/expertise about local services, entitlements etc..

Underuse of interactive techniques in the educational elements.

Limited use of programme resources (e.g. handouts, workbooks) to reinforce and extend learning.

Does not proactively support creation of on-going connections between group members, or facilitating connecting in with existing networks and communities.

Programme includes elements in addition to psychoeducation, significantly increasing the number of sessions.

Lower than expected take-up.

9.4 Autism psychoeducation programmes: recommendations

- Commissioning of autism-specialist diagnostic services should include the delivery of a group-delivered psychoeducation programme, with the option of offering in 1:1 format if required, and with sufficient resource provided for this. In line with NICE guidance that services for autistic adults should be multi-agency, and noting the potential impacts of psychoeducation programmes on both health and social outcomes, such programmes should be jointly commissioned.
- The provision of a psychoeducation programme post-diagnosis should be one of the core quality standards of adult autism diagnostic services.
- There should be national-level investment in the development, and evaluation, of a 'model' psychoeducation programme co-developed and co-facilitated by autistic adults and practitioners.

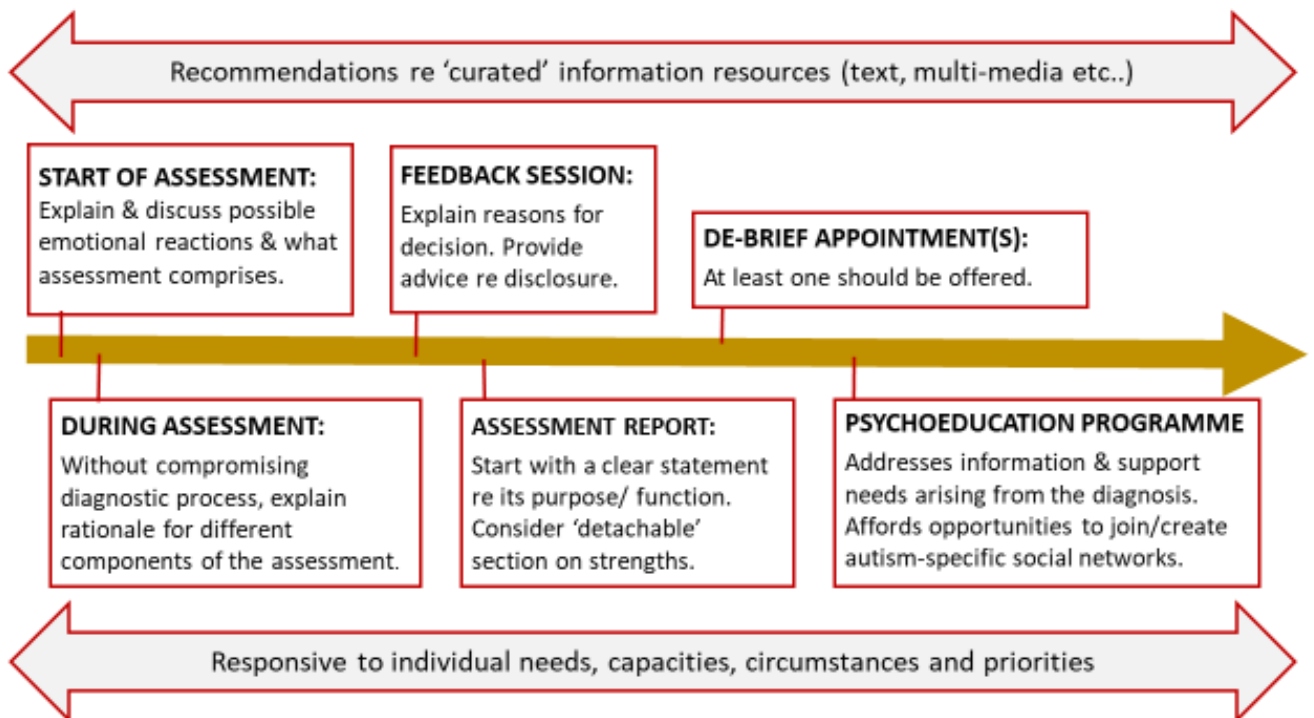
- Recognising this will take a period of time, until available we recommend services use an existing autism psychoeducation programme(s)^a, but also take into account findings and recommendations set out in this chapter on programme content and delivery.

10. Conclusions

The overall conclusions and recommendations on addressing the psychoeducation needs arising from an autism diagnosis are as follows:

1. Being diagnosed with autism, *in itself*, generates a range information and support needs, collectively referred to a psychoeducation needs. Meeting these needs should be regarded by policy makers and commissioners to be as important as timely access to an autism-specialist diagnostic assessment. This is because leaving such needs unrecognised and unattended has the potential to have a range of adverse impacts.
2. There are multiple points along the diagnostic pathway where services need to recognise and attend to psychoeducation needs, see Figure 6. Chapters 7 - 9 offer specific recommendations on the implementation and delivery of this pathway. We note that, whilst evidence generally supports group-delivered psychoeducation programmes, groups present additional challenges for autistic adults. Thus services should have the resource and capacity to deliver the programme via one-to-one sessions if required.

Figure 6: Meeting the psychoeducation needs associated with being diagnosed with autism: key interventions and practice across the diagnostic pathway



3. A key element of this pathway is the psychoeducation programme, a type of intervention applicable to any new diagnosis and with good evidence of benefit. Whilst we have identified a small number of autism psychoeducation programmes, none can currently be endorsed as a model programme. Thus investment in the development and evaluation of a 'model' psychoeducation programme for adults diagnosed with autism is required. Such work should build on existing programmes and practices, be informed by findings from this project, and developed by autistic adults and autism practitioners.

Finally, we note that this project's focus was on one element of post-diagnostic support: meeting the information and support needs which arise as a direct result of an autism diagnosis. This should not be taken to imply that other components of autism-specialist post-diagnostic support are not required. The current NICE guideline, and national policy and strategy documents, make clear recommendations regarding the different components of multi-agency, autism-specialist post-diagnosis support required, with more recently published research supporting this position.

11. References

1. Beresford B, Mukherjee S, Mayhew E, et al. Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: the SHAPE mixed-methods study. *Health Services and Delivery Research* 2020. DOI: 10.3310/hsdr08480.
2. Public Health E. *Autism Self-assessment Exercise 2016. Detailed Report and Thematic Analyses*. 2017. London: Public Health England.
3. Geurts HM and Jansen MD. A retrospective chart study: The pathway to a diagnosis for adults referred for ASD assessment. *Autism* 2011; 16: 299-305. DOI: 10.1177/1362361311421775.
4. Jones L, Goddard L, Hill EL, et al. Experiences of Receiving a Diagnosis of Autism Spectrum Disorder: A Survey of Adults in the United Kingdom. *Journal of Autism and Developmental Disorders* 2014; 44: 3033-3044. journal article. DOI: 10.1007/s10803-014-2161-3.
5. Lewis LF and Disorders D. A Mixed Methods Study of Barriers to Formal Diagnosis of Autism Spectrum Disorder in Adults. 2017; 47: 2410-2424. journal article. DOI: 10.1007/s10803-017-3168-3.
6. Digital NHS. Autism Waiting Time Statistics, <https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics> (2021).
7. Raymond-Barker P, Griffith GM and Hastings RP. Biographical disruption: Experiences of mothers of adults assessed for autism spectrum disorder. *Journal of Intellectual & Developmental Disability* 2018; 43: 83-92. DOI: 10.3109/13668250.2016.1262011.
8. Crane L, Batty R, Adeyinka H, et al. Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. *Journal of Autism and Developmental Disorders* 2018. journal article. DOI: 10.1007/s10803-018-3639-1.
9. Stagg SD and Belcher H. Living with autism without knowing: receiving a diagnosis in later life. *Health Psychology and Behavioral Medicine* 2019; 7: 348-361. DOI: 10.1080/21642850.2019.1684920.
10. Powell T and Acker L. Adults' Experience of an Asperger Syndrome Diagnosis: Analysis of Its Emotional Meaning and Effect on Participants' Lives. *Focus on Autism and Other Developmental Disabilities* 2016; 31: 72-80. DOI: 10.1177/1088357615588516.
11. Huws JC and Jones RSP. Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual & Developmental Disability* 2008; 33: 99-107. DOI: 10.1080/13668250802010394.
12. Leedham A, Thompson AR, Smith R, et al. 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism* 2019; 24: 135-146. DOI: 10.1177/1362361319853442.
13. Lewis LF. Exploring the Experience of Self-Diagnosis of Autism Spectrum Disorder in Adults. *Archives of psychiatric nursing* 2016; 30: 575-580. 2016/09/23. DOI: 10.1016/j.apnu.2016.03.009.

14. Punshon C, Skirrow P and Murphy G. The 'not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism* 2009; 13: 265-283. DOI: 10.1177/1362361309103795.
15. Hickey A, Crabtree J and Stott J. 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. *Autism* 2018; 22: 357-367. DOI: 10.1177/1362361316680914.
16. Bargiela S, Steward R and Mandy W. The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autism and Developmental Disorders* 2016; 46: 3281-3294. journal article. DOI: 10.1007/s10803-016-2872-8.
17. Neil-MacLachlan J, Fletcher J, Gregory D, et al. Lessons learned from running an adult autism diagnostic assessment service for 12 years. *Good Autism Practice (GAP)* 2014; 15: 71-78.
18. Rogers CL, Goddard L, Hill EL, et al. Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom. *Autism* 2016; 20: 820-831. DOI: 10.1177/1362361315611109.
19. Motlova LB, Balon R, Beresin EV, et al. Psychoeducation as an Opportunity for Patients, Psychiatrists, and Psychiatric Educators: Why Do We Ignore It? *Academic Psychiatry* 2017; 41: 447-451. DOI: 10.1007/s40596-017-0728-y.
20. Krysinska K, Curtis S, Lamblin M, et al. Parents' Experience and Psychoeducation Needs When Supporting a Young Person Who Self-Harms. *Int J Environ Res Public Health* 2020; 17: 3662. DOI: 10.3390/ijerph17103662.
21. Powell T and Acker L. Adults' experience of an Asperger syndrome diagnosis: analysis of its emotional meaning and effect on participants' lives. 2015; 31: 72-80.
22. Lewis LF. Realizing a diagnosis of autism spectrum disorder as an adult. *International journal of mental health nursing* 2016; 25: 346-354. 2016/03/05. DOI: 10.1111/inm.12200.
23. Tan CD. "I'm a normal autistic person, not an abnormal neurotypical": Autism Spectrum Disorder diagnosis as biographical illumination. *Social Science & Medicine* 2018; 197: 161-167. DOI: <https://doi.org/10.1016/j.socscimed.2017.12.008>.
24. Punshon C, Skirrow P and Murphy G. The 'not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. 2009; 13: 265-283. DOI: 10.1177/1362361309103795.
25. Colom F. Keeping therapies simple: psychoeducation in the prevention of relapse in affective disorders. *British Journal of Psychiatry* 2011; 198: 338-340. 2018/01/02. DOI: 10.1192/bjp.bp.110.090209.
26. Puts MT, Papoutsis A, Springall E, et al. A systematic review of unmet needs of newly diagnosed older cancer patients undergoing active cancer treatment. *Support Care Cancer* 2012; 20: 1377-1394. 2012/04/06. DOI: 10.1007/s00520-012-1450-7.
27. Hyun YG, Alhashemi A, Fazelzad R, et al. A Systematic Review of Unmet Information and Psychosocial Support Needs of Adults Diagnosed with Thyroid Cancer. *Thyroid* 2016; 26: 1239-1250. DOI: 10.1089/thy.2016.0039.

28. Lackie ME, Parrilla JS, Lavery BM, et al. Digital Health Needs of Women With Postpartum Depression: Focus Group Study. *J Med Internet Res* 2021; 23: e18934. DOI: 10.2196/18934.
29. Mojtabai R, Fochtmann L, Chang S-W, et al. Unmet Need for Mental Health Care in Schizophrenia: An Overview of Literature and New Data From a First-Admission Study. *Schizophrenia Bulletin* 2009; 35: 679-695. DOI: 10.1093/schbul/sbp045.
30. Ekhtiari H, Rezapour T, Aupperle RL, et al. Chapter 10 - Neuroscience-informed psychoeducation for addiction medicine: A neurocognitive perspective. In: Calvey T and Daniels WMU (eds) *Progress in Brain Research*. Elsevier, 2017, pp.239-264.
31. National Institute for Health and Care Excellence. *Common Mental Health Problems: Identification and Pathways to Care*. Clinical Guideline CG123. London: NICE, 2011.
32. National Institute for Health and Care Excellence. *Bipolar disorder: assessment and management. Clinical guideline [CG185]*. 2014.
33. Gómez-de-Regil L. Psychoeducation for Patients with Fibromyalgia: A Systematic Review. *Healthcare* 2021; 9. DOI: 10.3390/healthcare9060737.
34. Sin J, Gillard S, Spain D, et al. Effectiveness of psychoeducational interventions for family carers of people with psychosis: A systematic review and meta-analysis. *Clinical Psychology Review* 2017; 56: 13-24. DOI: <https://doi.org/10.1016/j.cpr.2017.05.002>.
35. Borek AJ, Abraham C, Greaves CJ, et al. Identifying change processes in group-based health behaviour-change interventions: development of the mechanisms of action in group-based interventions (MAGI) framework. *Health Psychology Review* 2019; 13: 227-247. DOI: 10.1080/17437199.2019.1625282.
36. Cipolletta S, Simonato C and Faccio E. The Effectiveness of Psychoeducational Support Groups for Women With Breast Cancer and Their Caregivers: A Mixed Methods Study. *Frontiers in Psychology* 2019; DOI: 10.3389/fpsyg.2019.00288.
37. Ugalde A, Haynes K, Boltong A, et al. Self-guided interventions for managing psychological distress in people with cancer – A systematic review. *Patient Education and Counseling* 2017; 100: 846-857. DOI: <https://doi.org/10.1016/j.pec.2016.12.009>.
38. Alhadidi MM, Lim Abdullah K, Yoong TL, et al. A systematic review of randomized controlled trials of psychoeducation interventions for patients diagnosed with schizophrenia. *Int J Soc Psychiatry* 2020; 66: 542-552. 2020/06/09. DOI: 10.1177/0020764020919475.
39. Bevan Jones R, Thapar A, Stone Z, et al. Psychoeducational interventions in adolescent depression: A systematic review. *Patient Educ Couns* 2018; 101: 804-816. 2017/11/07. DOI: 10.1016/j.pec.2017.10.015.
40. Tursi MFdS, Baes CvW, Camacho FRdB, et al. Effectiveness of psychoeducation for depression: A systematic review. *Australian & New Zealand Journal of Psychiatry* 2013; 47: 1019-1031. DOI: 10.1177/0004867413491154.
41. Beardslee WR, Gladstone TRG, Wright EJ, et al. A Family-Based Approach to the Prevention of Depressive Symptoms in Children at Risk: Evidence of Parental and Child Change. *Pediatrics* 2003; 112: e119-e131. DOI: 10.1542/peds.112.2.e119.

42. DeMaso DR, Marcus NE, Kinnamon C, et al. Depression experience journal: a computer-based intervention for families facing childhood depression. *J Am Acad Child Adolesc Psychiatry* 2006; 45: 158-165. 2006/01/24. DOI: 10.1097/01.chi.0000190353.98570.fe.
43. Samuelowicz K and Bain JD. Revisiting academics' beliefs about teaching and learning. *Higher Education* 2001; 41: 299-325. DOI: 10.1023/A:1004130031247.
44. Hodkinson A, Bower P, Grigoroglou C, et al. Self-management interventions to reduce healthcare use and improve quality of life among patients with asthma: systematic review and network meta-analysis. *BMJ* 2020; 370: m2521. DOI: 10.1136/bmj.m2521.
45. Captieux M, Pearce G, Parke HL, et al. Supported self-management for people with type 2 diabetes: a meta-review of quantitative systematic reviews. *BMJ Open* 2018; 8: e024262. DOI: 10.1136/bmjopen-2018-024262.
46. National Institute for Health and Care Excellence. *Autism Spectrum Disorder in Adults: Diagnosis and Management*. Clinical Guideline 142. London: NICE, 2012.
47. National Institute for Health and Care Excellence. *Autism spectrum disorder in under 19s: support and management. Clinical guideline [CG170] (Last updated 14 June 2021)*. 2013.
48. National Institute for Health and Care Excellence. *Common mental health problems: identification and pathways to care. Clinical guideline [CG123]*. 2011.
49. Russell G, Stapley S, Newlove-Delgado T, et al. Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *Journal of Child Psychology and Psychiatry* 2021; n/a. <https://doi.org/10.1111/jcpp.13505>. DOI: <https://doi.org/10.1111/jcpp.13505>.
50. Patient Empowerment Network. The Power of Content Curation for Healthcare Communities, <https://powerfulpatients.org/2016/04/28/the-power-of-content-curation-for-healthcare-communities/> (2016).

Appendix 1: Characteristics of autistic adults involved in consultation work

Age	
Range	21-64 years
Median	39 years
Age when first diagnosed	
Total sample (n=26)	Range = 1- 61 years, median = 33 years
Diagnosed > 18 years (n=22)	Range = 19- 61 years, median = 40 years
Diagnosed < 18 years (n=4) ¹	Range = 1-9 years, median = 6 years
Years since diagnosis	
Total sample	Range 1-26 years, median 6 years
Diagnosed > 18 years	Range 1-16 years, median 4 years
Diagnosed < 18 years	Range 21-26, median 23 years
Attended adult autism psychoeducation group?	
No	16
Yes	10
Gender	
Male	13
Female	9
Agender	1
Agender/neutrois	1
Non-binary	1
Non-binary trans masculine	1
Ethnicity	
White British	
South East Asian	
Mixed ethnicity	

¹ One individual diagnosed in childhood and re-diagnosed as an adult