

**Workshop 2: Family Follow up Meetings
Pack for Professionals
Scottish Autism Strategy Conference 26th March 2019**

Post-diagnostic support for parents/ carers of children in mainstream schools following an ASD diagnosis in Edinburgh

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Workshop 2: Family Follow Up Meetings: A multi-disciplinary model for support for children and families in the months following ASD diagnosis

Immediately following a new diagnosis for their child or young person, families in Edinburgh are offered a one-off, one hour meeting with two autism skilled professionals (representing health and education). The meetings centre on (1) questions parents / carers have following the diagnosis (2) signposting to individually relevant resources and information and (3) discussion about how support is co-ordinated locally with discussion on making the most of local processes.

In this workshop we will share our model; share materials used; summarise feedback from participating families and benefits of listening to issues raised by families. The workshop is likely to be of most interest to those providing or planning support to families following ASD diagnosis.

Family Follow Up Meetings Pack Contents

Resource Bank

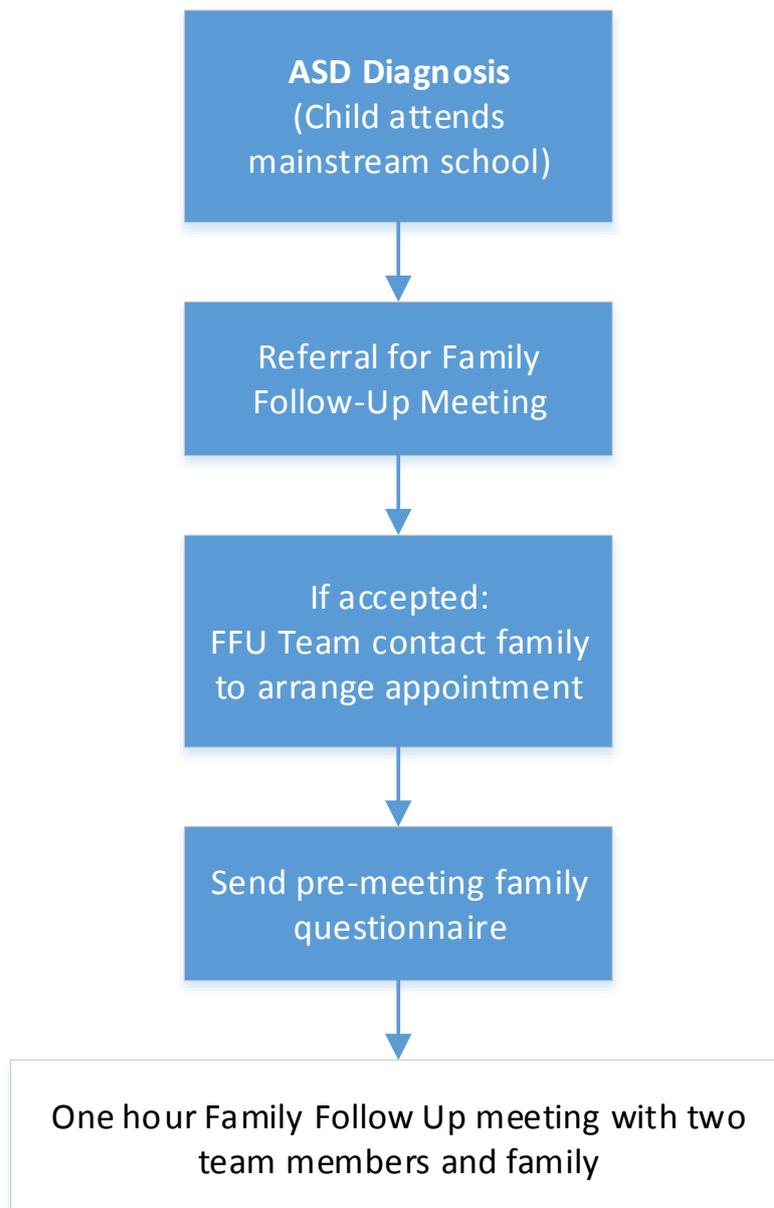
In order to run family follow up meetings we recommend:

- Deliver training to health and Education staff running meetings (powerpoint available in request)
- Set up your administration process
- Make up local guidance and packs to send out to families with leaflets and contact information

This pack contains documents you might find helpful:

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Family Follow Up Meetings Process



Post meeting Actions

Meeting summary for family

Resource pack for family

Meeting summary and information for school

Alternative arrangements are in place for:

- Pre-school children
- Those attending Special Schools or classes
- Support for children and young people regarding their diagnosis of ASD

Family Follow Up Meetings Information Sheet

Post-diagnostic support for parents/ carers of children in mainstream schools following an ASD diagnosis in Edinburgh

When children are given an autism diagnosis through NHS teams, this can be an especially difficult time for families. It is recommended that a *Child Planning Meeting* is held either as soon as concern is recognised or soon after a child receives a new ASD diagnosis.

Family Follow up meetings complement the Child Planning Process and are offered to parents and carers shortly after diagnosis. This flier provides information for school staff and support services about family follow up meetings.

What is a family follow up meeting?

- It is a one off meetings for families of children in mainstream primary and secondary schools who have recently received a diagnosis of an autism spectrum disorder.
- Families are offered an opportunity at the meeting to talk to trained staff from the NHS and Education services who have specialist knowledge of ASD and supports currently available (the Family Follow Up team).
- The family follow up team do not meet the child or have an ongoing role with the family.
- Families are usually referred by the NHS diagnostic team at but can also be referred by visiting services or schools.

There are three main purposes to the meeting:

- An opportunity for the parents/ carers to ask questions specifically related to the new diagnosis and to share their own perspective on the experience of having a child with ASD.
- Signposting and information sharing about the range of relevant resources and supports available to children with ASD, siblings and families.
- Sharing information with families about how support is co-ordinated in Edinburgh through the *Getting It Right* integrated Child Planning process.

Following the meeting:

- The family is sent a summary of the discussion following the meeting.
- If the family give permission this is also shared with other professionals working with their child.
- A cover letter is sent to the school which signposts to further supports and resources. It is hoped that the information shared can be used to inform the child planning process.
- School and support staff can contact the family follow up team via the email address below.

Family Follow Up Meetings Referral

In order to make a referral for a family follow up meeting, please send the following information:

Child Name	
Child Date of Birth	
Parent/ carer name(s)	
Address	
Home contact telephone number(s)	
Name of School attended and stage	
Has consent been given for referral and to share this information between health and education services	
Diagnosis given and date diagnosed	

Family Follow Up Meetings Family Questionnaire

The following questionnaire is sent to families in advance of the meeting. We recognise that each parent is different and for some it helps, for other it doesn't. There is no expectation that they will have filled it in

- This meeting might be different to other meetings they have attended and the questionnaire helps set expectations
- Increasing predictability for families, reduces anxiety
- Thinking in advance can help families raise the important questions to them
- It opens up the chance to discuss strengths, concerns, questions and solutions relevant to them in their circumstances

Parent Appointment Letter Template - Individual Meeting

Name
Address
City
Postcode

Date

Dear

Re: Family Follow up Meeting for _____

Following your child's diagnosis of an Autism Spectrum Disorder, we would like to invite you to a family follow up meeting on **Day, Date and Time**.

The meeting will take place at **(ADDRESS)** Please confirm if this date and time is suitable for you or not.

About the meeting

This is a meeting with members of the multi agency team providing support to children with ASD in mainstream schools in Edinburgh. This meeting aims to:

- Offer you an opportunity discuss information or services that would be supportive to you
- Address any concerns you may have or questions you may wish to ask in relation to **Child's Name** and **his/her** diagnosis, his communication, social interaction, learning or behaviour
- Signpost you towards key sources of support and explain how we offer co-ordination of future support in Edinburgh

You may find it helpful to bring someone with you, partner, friend, family member, health visitor or key worker if you have one. We have enclosed an information sheet about the meeting.

It is not necessary to bring **Child's Name** along to the meeting but if you can make no alternative arrangements please let us know beforehand.

Questionnaire

I am enclosing a brief questionnaire. If you feel it would be helpful, please could you complete this and bring it to the meeting, thank you.

In the meantime if you have any questions please don't hesitate to call (NAME) on (TEL). If we are unavailable, a member of the admin team will take a message and we will return your call.

Yours sincerely

Name
Service Administrator
Enc

Parent Appointment Letter Secondary Group Meeting

[Address]

[date]

Dear [parents names]

You were referred for an individual family follow up meeting following your son/ daughter being diagnosed with autism spectrum disorder and are still on our waiting list.

In order to address the time parents are waiting for such appointments, we would like to invite you to a Secondary Family Follow Up group session for parents. These will be held:

At:

Date:

Time: a choice of times (see below)

Who should attend?

These sessions are for parents or carers and you are welcome to bring a friend or support person

They are not for young people with ASD

What will happen at the session?

The session will cover

- Questions families have following ASD diagnosis
- The Young Person's Planning Process – how support and transitions in health are co-ordinated in Edinburgh
- Information parents may find helpful with regard to
 - * Learning more about autism
 - * Financial Benefits
 - * Third sector supports
 - * Family supports
 - * Leisure and community supports
 - * After school supports

You will be given an information pack to take away

How do I book my place?

Please reply to this letter by phone, email or by returning the tear off slip below, with the following information:

Secondary Family Follow Up Group session reply slip 2017

Names of parents/ carers attending:

Child's name:

Address:

Please Tick

I/ we no longer wish to attend a family follow up meeting

I/ we wish to attend the meeting on the afternoon of [date]

I/ we wish to attend the meeting on the afternoon of [date]

Parent Questionnaire for Family Follow Up Meeting

B. INFORMATION

Following diagnosis you will probably have been given some information about Autism Spectrum Disorders and local supports and benefits. You may have also read more or spoken to others to gather information. At present:

Do you have any queries about information you have read or heard?

Is there anything you or family members would like more information about at present?

C. CO-ORDINATION and SUPPORTS

You and your child may have no current needs for support or co-ordination of these. If there is a need for support, a child planning meeting is at school and the school will co-ordinate these.

Who is currently involved in supporting you and your child?

Is there any support need that you feel is not met at present?

Have you had a child planning meeting at school?

D. OTHER ISSUES

Are there any issues for the wider family that you would like to discuss?

Are there any other issues you would like to discuss at the family follow up meeting?

Please bring this with you to the meeting on _____

If you have any queries, prior to the meeting please contact _____

Family Follow Up Meeting Report Template

Summary of Family Follow Up Meeting for: xxxx

Held at:

Date:

Present at Meeting:

The intervention team members X and X introduced themselves and briefly explained what we do. We explained that we are from a larger multi-agency team, made up of representatives from the following agencies:

Education

Speech and Language Therapy

Occupational Therapy

Community Child Health

Social Work

Child and Adolescent Mental Health Services (CAMHS)

The team work together to support children of school age in mainstream schools within City of Edinburgh.

Today was a one off meeting following your child's recent diagnosis. We were able to offer advice and information, and the opportunity to discuss any issues arising from your child's diagnosis.

We explained the way in which support is coordinated within Edinburgh and discussed appropriate next steps for you and your child.

You told us about:

Support and progress at home and school:

- **(summarise key points)**

Diagnosis:

XXXX received a diagnosis of ASD in 201X. You were not surprised by the diagnosis/ make a comment as relevant

Queries and concerns:

- **(summarise key points)**

Family Follow Up Meeting Report Template (continued)

We discussed the following sources of information and support (add and delete as required)

National Autistic Society, holiday playschemes in Edinburgh, Siblings Groups, Scottish Autism 'Right Click' programme, Hanen 'Talkability', Edinburgh Leisure, Action Group, Barnardo's After School Clubs, Family Fund, VOCAL, FAIR, Enquire and Parent Information sessions.

An information pack with details of these supports is included with the letter for families

Action Points

- **(list any actions agreed, making sure not to delegate to others not present)**

Onward referrals

- Either – Child planning meetings are in place for XXXX and the next meeting is planned for...
- Or - The team request that the school hold a Child Planning Meeting in the near future to discuss issues arising from XXXX's diagnosis. It is hoped that some of the information in these minutes might help to inform planning for XXXX.

name

name

Family Follow Up Team

c.c.

Parents:

School:

CCH: Dr

SLT:

Psychological Services:

Other:

Family Follow Up Meeting Head Teacher Cover Letter

Date

Dear Mr/s

We enclose the notes from a family follow up meeting with the parent of xxx (Px/ Sx)

We offer parents/ carers a one off *Family Follow Up meeting* when their school age child receives a diagnosis of autism spectrum disorder. Members of the multi-agency support team for school aged children with ASD in Edinburgh meet with families on a single occasion to:

- Signpost or provide relevant Information about ASD and local supports for families and children, benefits and entitlements,
- Answer questions about the co-ordination of support within Edinburgh and the way services are integrated
- Answer questions that have arisen for the family as a result of the diagnosis
- Make links with school and other support services if any queries are raised by the family about further referral for support at home or school

The outcome of the meeting is summarised and circulated with parental permission.

The team also provide support and training to colleagues in schools and we would like to draw your attention to the following resources available to staff in your school:

- The Autism Toolbox online www.autismtoolbox.co.uk
- The CIRCLE resources
- Socialthinking.com
- The Visual Support Project (Training request to ASL Service Leader)
- ASD Whole School Training (Training request to ASL Service Leader)
- Relevant Level 2 training within the CPD directory

We are aware that you already have the child/young person's planning meeting process in place for xxx and information contained may be useful in future planning.

We are not able to attend Child/ Young Person's Planning Meetings for the families we meet but members of the team involved with each child will be glad to be invited in the usual manner.

This is a one off meeting, providing a summary of issues raised by the family on the day. We welcome you to contact us with any queries over the information contained.

Kind Regards,

Name

ASD Family Follow Up team

Guidance for staff running Family Follow Up Meetings

Before meeting

Admin staff will:

- Update the Family Follow Up list, with children's names and appointment dates and will circulate to Family Follow Up team every 4 - 6 weeks
- Book meeting rooms
- Send out invitation letter and questionnaire to parents

Family Follow Up staff will:

- Identify and share with admin staff available time slots for meetings to be booked into
- Ensure a minimum of two members of staff can attend
- Know child's name, date of birth, school and stage
- Set up room, with personal safety in mind

Introductory information

1. Introduce selves and role and let family introduce themselves
2. Explain that we represent a wider team who support children with ASD and their families who include ASL Service, SLTs, OTs, EPs, CAMHS, Paediatricians, Social Work
3. Explain how the meeting works:

This is a one off meeting and we have one hour to focus on three things

- Questions following diagnosis
- The child planning process and the way support is co-ordinated
- ASD supports locally

Say that:

- We don't collect detailed information on your child in advance of the meeting but rely on the information you share with us today
- We will take notes and send you these together with any leaflets or details of websites we refer to
- It might feel like a lot of information but don't feel you have to go away and act on it all at once
- We don't give advice or make referrals but will signpost to the appropriate route for support
- Ask for permission to share this with the school and other professionals
- Check contacts to share the written summary with

NB whilst not offered as a matter of course, some families may wish to see a draft before the summary is circulated

Guidance for staff running Family Follow Up Meetings

Introductory discussion

Ask:

- Have you brought the questionnaire along? – it is fine if not, it's just to orientate families to the topics we might cover
- If there is anything in particular they would like to discuss (refer to questionnaire). We usually then start with their priority and let the discussion be led by the family

Staff should be aware that we only have the parent perspective; avoid direct advice, focus on signposting

Running the Meeting

A. Questions about the diagnosis/ issues for the family

- Indicate that we may be able to answer queries. If we are not able to, or if the query is outwith the remit of this meeting we may advise taking it to the appropriate colleague.
- Some examples of FAQ's and possible answers are outlined at the end of this guidance.

B. Child Planning Process (Primary)

- Ask if the family have had a Child Planning Meeting and how that has gone for them
- Make sure they know the meeting can be used to raise issues at home as well as school. The school may not be able to resolve an issue in which case the team can signpost the family and/or seek support through the agreed local process
- If needed we can explain the purpose of Child Planning Meetings
- We can explain that the family can request a meeting if they wish to - this should be arranged within a reasonable length of time
- It may be helpful to explain to families why all professionals don't attend all meetings – a small number of staff provide support for all children with ASD in Edinburgh therefore they have to prioritise the meetings they attend. If a parent feels the input of one particular professional is important for a particular meeting, they can request that it is arranged for a time when they may be able to be there
- It can help to reinforce the need to have a plan for communication with the teacher, which can be either a diary, a weekly phone call, an email

B. Child Planning Process (Secondary)

- Ask if the family have had a Young Person's Planning Meeting (or equivalent meeting at school) and how that has gone for them
- If needed we can explain the purpose of Young Person's Planning Meetings
- Make sure they know the meeting can be used to raise issues at home as well as school. The school may not be able to resolve an issue in which case the team can signpost the family and/or seek support through Education and partner support agencies
- We can explain that the family can request a meeting if they wish to - this should be arranged

Guidance for staff running Family Follow Up Meetings

within a reasonable length of time

- It may be helpful to explain to families why all professionals don't attend all meetings – a small number of staff provide support for all children with ASD in Edinburgh therefore they have to prioritise the meetings they attend. If a parent feels the input of one particular professional is important for a particular meeting, they can request that it is arranged for a time when they may be able to be there
- It can help to reinforce the need to have a plan for communication with the school, which can be either a diary, a weekly phone call or an email. The school usually provide the names of two key staff members who would be the regular link.
- Check the child/ family have a minimum of 2 named people to approach for support in school. Ideally one should be from senior management.

C. Signposting to ASD supports locally (See table below)

Points to consider during discussion:

- Families come with different levels of emotional state and knowledge and the meeting should be responsive to them
- In the meeting we aim to be solution focused and to listen to the family. We cannot teach them all they need to know but can help shape their thinking about having one priority at a time, or how to seek support that they need
- We can use the report to highlight support needs identified by the family to the team working directly with them
- FFU meetings are specifically to offer information and support to parents/carers and if the family have concerns that their child would benefit from a similar meeting, this should be discussed with the team around them at the CPM or YPPM.
- We can use the report to highlight support needs identified by the family to the team working directly with them
- The discussion should focus on signposting the family to the right person already supporting them, rather than trying to answer individual issues
- We must be realistic and not promise things we don't have control over
- Remain professional, avoid any criticism of colleagues (direct or implied)

Concluding

Say:

- That's all we have time for today
- Thanks for coming
- We will send out the minutes and information pack
- You have our contact details if you have further queries

Guidance for staff running Family Follow Up Meetings (Primary stage)

After the meeting:

- Write up the meeting summary (following 'Family Follow Up Summary Writing Guidance')
- Send to a Family Follow Up team member to check
- Edit a copy of the Head Teacher Cover Letter to school and send to admin staff with a checked copy of the summary
- Admin will make up an information pack and send this together with a copy of the summary out to the family; copies of the summary will also be sent to all on agreed cc list; a copy of the summary together with the HT cover letter will be sent to the school

Support	Information to share
<p>Disability Living Allowance (related charities to help complete form: Action Group, Kindred, Fair, Vocal, Enquire)</p> <p>Telephone: 0845 712 3456 Monday-Friday 8am-6pm www.gov.uk</p>	<p>Advise families to apply, although NB we cannot promise all will be successful, many are.</p> <p>Information about DLA can be found at www.dwp.gov.uk Request a form by phoning 0845 7123456</p> <ul style="list-style-type: none"> • Advise against downloading the form. The DWP will date stamp a date sent • They will also date stamp a date for return of form • Families should call one of these organisations - Action Group, Fair, Vocal, Enquire and request a meeting to help complete the form • Tell the organisation the return date for the form • If one organisation cannot provide support, call another
<p>Section 23 Assessment 0131 200 2327</p>	<ul style="list-style-type: none"> • Families can request a Section 23 Assessment from Social Care Direct. This may enable them to access some respite support and other services. They can
<p>Scottish Autism - Right Click Tel: 01259 720044 autism@scottishautism.org www.scottishautism.org</p>	<ul style="list-style-type: none"> • A free 5 week online training course for families • You can select either Early Years, Teenage Years or Women and Girls • Once you register, you will be given a mentor to email for advice and support • You will have access to new information each week, with videos to watch • The mentor can direct you to those covering topics you may be most interested in
<p>National Autistic Society – website and publications www.autism.org.uk</p>	<ul style="list-style-type: none"> • The recommended source of accurate information for families • Has a good summary about Social Stories • Holds a good publications list of books to read or buy
<p>Lothian Autistic Society – Family Days, social groups, Parent to Parent Lothian Autistic Society Unit 22 Castlebrae, 40 Peffer Place Edinburgh, EH16 4BB Tel: 0131 6613834 www.lothianautistic.org</p>	<p>LAS is the local parent support organization</p>

Guidance for staff running Family Follow Up Meetings (Primary stage)

Playschemes	Share up to date information about subsidised holiday playschemes for children with ASN
Autism Network Scotland www.autismnetworkscotland.org.uk	Signpost for information about what is happening around Scotland SWAN Network for Women and Girls
Kindred 7 Rutland Court Lane Edinburgh, EH3 8ES Telephone Helpline & Enquiries: 0131 536 0583 www.kindred-scotland.org	Families can access: <ul style="list-style-type: none"> • Advocacy • Helpline • Advice • Support with DLA applications
Fair 95 Causewayside Edinburgh EH9 1QG 0131 662 1962 fair@fairadvice.org.uk	Families can access: <ul style="list-style-type: none"> • Advice and information • Support with DLA applications
Vocal 8-13 Johnston Terrace Edinburgh EH1 2PW Tel: 0131 6627625 www.vocal.org.uk centre@vocal.org.uk	Families can access: <ul style="list-style-type: none"> • Information and advice • Emotional support • Training • Advocacy • Counselling • Group work
Enquire Children in Scotland 5 Shandwick Place Edinburgh EH2 4RG Telephone helpline: 0845 123 2303 info@enquire.org.uk www.enquire.org.uk	Families can access: <ul style="list-style-type: none"> • Advice and information on Additional Support for Learning • Support with DLA applications
Action Group Norton Park Centre 57 Albion Road EH7 5QY 0131 4752316 www.actiongroup.org.uk	Families can access: <ul style="list-style-type: none"> • Advice and information • Support with DLA applications

Guidance for staff running Family Follow Up Meetings (Primary stage)

<p>Family Fund 08449 744099 info@familyfund.org.uk www.familyfund.org.uk</p>	<p>A means tested government fund that families can apply to each year, for items up to around £300 for something that makes life easier for a child with ASN. It could be a washing machine, a new bed, a trampoline, a zoo membership or an iPad.</p> <p>The availability of funds varies and it is worth checking regularly</p> <p>Eligibility criteria can change – check the website</p>
<p>Take a Break Fund 0190 4571093 www.takeabreakscotland.co.uk info@takeabreakscotland.org.uk</p>	<p>A government fund (non means tested) that any family with a child with ASN can apply to for help with a holiday or break. This is administered by the same people as the family fund so the forms look similar but you can apply for both.</p> <p>The availability of funds varies and it is worth checking online regularly</p> <p>Families have used money e.g. to buy camping equipment, to hire a caravan with an extra room, to go to Legoland or towards a foreign holiday.</p>
<p>Siblings groups</p> <p>Barnardo's 11 Oxfords Road North EH14 1ED 0131 446 7000 www.barnardos.org.uk</p>	<p>Run at various times by:</p> <ul style="list-style-type: none"> ● Action Group ● Barnardo's <p>Check individual websites for current availability</p>
<p>Edinburgh Leisure Disability Sport and Physical Activity Development Officer Edinburgh Leisure Vantage Point 3 Cultins Road EH11 4DF 0131 458 2162 www.edinburghleisure.co.uk highflyers&jumpin@edinburghleisure.co.uk</p>	<ul style="list-style-type: none"> ● The Development Officer can discuss ways to support your child to access leisure activities. They can advise on suitable classes and opportunities for additional assistance in classes. ● Newsletter ● Link to Activ8 at Gracemount Leisure Centre activity days for children with ASN on Saturdays – alternates primary and secondary
<p>The Yard 22 Eyre Place Lane Edinburgh EH3 5EH Tel: 0131 4764506 info@theyardscotland.org.uk</p>	<ul style="list-style-type: none"> ● Adapted play area in Eyre Place, Canonmills area ● Drop in sessions on Friday pm and Saturdays ● Other clubs run - info from The Yard ● Football club
<p>Hanen Talkability (if under 8 years)</p>	<p>A programme for parents of verbal children with ASD aged 4-8 years to teach strategies to support social interaction and peer relationships. Referral through SLT.</p>
<p>Autism Parent Information Sessions (run by ASL Service/ AHPs)</p>	<p>Early years/ primary/ secondary info sessions for families run twice a year each.</p> <p>Each has 5-7 sessions. Parents can come to one or all. Topics are shared in advance.</p> <p>Fliers sent out to City of Edinburgh mainstream schools and professionals about 4 weeks before each run</p> <p>Parents self refer</p>
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Guidance for staff running Family Follow Up Meetings (Primary stage)

<p>First Hand Strathmore Business Centre Hopetoun Gate 8b McDonald Road Edinburgh EH7 4LZ 0131 523 1322 www.firsthandedinburgh.org.uk</p>	<ul style="list-style-type: none"> • Offer befriending or support in the family home for children with disabilities allowing parents or carers some respite from their caring responsibilities • Support and advice for parents who have few support networks of their own • Working with parents to help establish routines with their children • Information and support to access other agencies appropriate to the needs of the family
<p>Cinema screenings and card</p>	<p>Autism friendly screenings – lights up, sound down and allowed to bring own snacks; moving around accepted. Can be distracting for some.</p> <p>Cinema Card for those in receipt of DLA we can send form – gets carer in free</p>
<p>Bus Pass</p>	<ul style="list-style-type: none"> • For those in receipt of DLA • Children with ASD and a carer travel free. Application forms at local library
<p>Edinburgh Airport</p>	<p>If you contact them in advance of travel they can offer special assistance and resources</p>
<p>Barnardo's /ASL Service After School Club for : P4-7 Secondary</p>	<p>ASD specific After school club runs Thursdays 16:00-17:30 See leaflet for referral details</p>

Guidance for staff running Family Follow Up Meetings (Secondary stage)

Transition into adulthood

If your child is going on to study at college or at university find out about support available for them. Colleges are usually well set up for supporting young people with additional support needs. Universities are usually very helpful as well and will have a disability office that you should go to if your child agrees to do so.

<p>Number 6</p> <p>24 Hill Street, Edinburgh, EH2 3JZ Email: number6@aiscotland.org.uk Telephone: 0131 220 1075</p> <p>http://www.number6.org.uk/</p>	<ul style="list-style-type: none"> • Number 6 is a service (One-Stop Shop) for adults (16 and over) with High Functioning Autism (HFA) or Asperger Syndrome (AS) who live in the Lothians and the Borders. • There are three strands within Number 6: • One-Stop Shop (providing free social opportunities and 1-1 advice and support on a range of issues); • Outreach (funded packages of 1-1 support); • Housing. • If interested in using the services at Number 6 book an appointment to meet with a member of staff, who will give you a brief induction to the resources available.
<p>Into Work</p> <p>http://www.intowork.org.uk/</p> <p>IntoWork, Norton Park, 57 Albion Road, Edinburgh EH7 5QY Tel 0131 475 2600, Fax 0131 475 2379, enquiries@intowork.org.uk</p>	<p>A specialised employment support service for disabled jobseekers across Edinburgh, East, West and Midlothian. To be eligible to receive our services you must be aged between 16 and 65 and meet the following criteria:</p> <ul style="list-style-type: none"> • Have a disability or health condition and be seeking work within the City of Edinburgh travel-to-work area. • Motivated to gain open paid employment. • Live in Edinburgh, Midlothian or East Lothian and can access IntoWork services in Edinburgh or Haddington. • Be able to self travel or have your own travel arrangements. • Give your consent to the referral.
<p>Autism Parent information sessions</p> <p>(Education/ AHP)</p>	<ul style="list-style-type: none"> • ASD Parent information sessions for families whose children attend mainstream secondary schools in Edinburgh run twice a year each. • Each has 5-7 sessions. You can come to one or all. Topics are shared in advance. • The sessions are advertised through fliers shared with schools and health professionals. • Parents self refer
<p>Teen Triple P Parent Programme</p> <p>Contact Jillian.Hart@edinburgh.gov.uk</p>	<ul style="list-style-type: none"> • ASD specific Parenting programme runs when possible
<p>Skills Development Scotland</p> <p>9 Shandwick Place, Edinburgh, EH2 4SD</p> <p>https://www.myworldofwork.co.uk/ Phone: 0131 718 2040</p>	<ul style="list-style-type: none"> • Provide support and information with post school options, such as further education. • They can support with any applications and provide careers advice and information.

Guidance for staff running Family Follow Up Meetings (Secondary stage)

<p>Project Search http://www.edinburgh.gov.uk/info/20163/opportunities_for_young_people/1204/project_search Phone: 0131 529 3139 Email: project.search@edinburgh.gov.uk</p>	<ul style="list-style-type: none"> • A full time training program run by the council, NHS and college. As it follows the college year information sessions and applications are around February/March Ask Skills Development Scotland about this
<p>Local Area Co-ordination Team http://www.edinburgh.gov.uk/info/20079/disabilities/476/local_area_co-ordination Referrals via Social Care Direct: 0131 200 2324 or socialcaredirect@edinburgh.gov.uk</p>	<ul style="list-style-type: none"> • Provide support for people who have physical or learning disabilities, acquired brain injury or autism to learn to travel independently or to link in with groups or activities in their community.
<p>Grassmarket Community Project, 86 Candlemaker Row, Edinburgh, EH1 2QA http://www.grassmarket.org Phone: 0131 225 3626 Email: info@grassmarket.org</p>	<ul style="list-style-type: none"> • A range of activities, classes and supportive group experiences to increase confidence and re-connect members with themselves, their community and society. This includes art, drama, music, photography, reading group, sewing, IT, a job club and many more
<p>Enable Edinburgh & Lothians Support Services, Birch House, 10 Bankhead Crossway South, Edinburgh, EH11 4EP</p>	<ul style="list-style-type: none"> • Provides a range of flexible services for adults including: Employment services, Leisure and social activities, Sex and Relationship Forum and Courses and Support with future planning
<p>Junx10n Donaldson's, Preston Road, Linlithgow, West Lothian, EH49 6HZ www.donaldsons.org.uk/junx10n.aspx Phone: 01506 841 469 Email: ccolvin@donaldsons.org.uk</p>	<p>A new Employability Service, based in Linlithgow, for young people between the ages of 16-25. The service provides tailored personal development and employability mentoring which supports work-based and/or further education placements.</p>
<p>Canongate Youth Project South Bridge Resource Centre, 6 Infirmary Street, Edinburgh, EH1 1LT http://www.canongateyouth.org.uk/ Phone: 0131 556 9389/9719 Email: admin@canongateyouth.org.uk</p>	<ul style="list-style-type: none"> • Offer a number of activities and groups for young people as well as an employability and • training service. They also run a cafe where young people can gain training and work • experience.

Frequently Asked Questions and Possible Answers

NB:

- **This is only broad guidance .**
- **The most important thing is to listen to the family and let them reach their own decisions.**
- **Some families need more detail, others need a short simple response.**
- **Our role as professionals is to make this judgement and check in with families about how the information was that was shared.**
- **Stay within your professional boundaries and if you do not know, say so.**
- **Do not hypothesise or guess. You can say, I suggest you talk to xxx about this question but I will note in the summary that you raised it.**

Where is my child on the spectrum?

- We can't give a clear number or statement of where any person is on the spectrum, as there are so many factors to consider.
- **SKILLS:** These might include intellectual ability or the degree of difficulty with communication, social interaction, anxiety or inflexibility.
- **ENVIRONMENT:** A child might do very well because their environment meets their needs regardless of their inbuilt level of skill. This can change over time and is very individual.

When and how will I tell my child/ other children in the family about their diagnosis?

- There is no right or wrong answer. Ask the parent what they currently feel they want to do/ say.
- If a child or sibling is asking about why they are different, parents might want to talk to them more about it rather than avoid the issue. Reassure that they don't need to give more information than is currently being asked for. Children might be happy with pretty minimal information. Parents can share on a 'need to know' basis.
- If they feel they'd like to tell – we can suggest books that might be helpful (booklist attached).
- If they don't want to – that's ok too. They might want to talk about different people's strengths and difficulties instead.
- Parents might want to feel comfortable and well informed about the diagnosis before sharing with child or others. Meeting other parents may be of help.
- Barnardo's siblings groups might also be helpful

Should I tell the other parents in my child's class?

- Again, there is no right or wrong answer. This is down to parents' own preferences and individual situation/ the other parents. Talk around this if the parent wishes to. Let them reach their own decision.
- Other possible answers:
- Parents may wish to share with some, who the child is more friendly with.

Frequently Asked Questions and Possible Answers

- Rather than share the label, parents may prefer to share the kinds of needs he has and ways to support these.
- The team working with the child may be able to advise on individual circumstances.
- Reassure parents they have the right to choose to keep information private or to share it.
- Once shared, we can't 'untell'

His melatonin was working but it stopped working / I am interested in special diets – what should I do?

- With any medical questions we should advise parents to contact their paediatrician/ other doctor involved.

We're thinking of trying (a specific intervention).

- Objective information can be shared (i.e. information from evidence based guidelines such as SIGN Guidelines).
- It's okay to say you don't know.
- Allow families to talk about their reasons for considering the intervention.
- It may be appropriate to identify existing supports and adaptations that may help to meet that need. As appropriate refer to NAS website (www.autism.org.uk), Research Autism, SIGN Guidelines and relevant colleagues (e.g. paediatrician).
- Note in the minutes that this question has been raised.

What can I do about bullying?

- Acknowledge this concern.
- Support for situations involving bullying are best planned for and provided in the context in which it is believed to be happening and by the people who know the child and context well.
- Ask families whether they have a home-school diary or a regular communication system in place – advise that this would be helpful. Stress the importance of trying to get the whole picture.
- Parents may wish to request a meeting with school staff to share their concerns and make a clear written plan for a way forward.

What should I do if I don't think the school are taking my concerns seriously?

- Advise parents to share their concerns with the school
- If parents feel it is appropriate, request a Child Planning Meeting. This will enable them to share their concerns with the wider group supporting their child.
- Other sources of support may include the Educational Psychologist for the school or advocacy provided by third sector organisations.

Frequently Asked Questions and Possible Answers

Questions about 1:1 and PSA support in school

- Explain that support can take many forms. Sometimes indirect support can allow the child to develop skills of independence. Structures such as a visual timetable and clear routines can enable a child to participate effectively within the class.
- Some children with additional support needs will have PSA support allocated to them. This is usually provided through the support budget managed within the school. Should the parent feel their child needs support for a particular part of the school day, encourage them to raise this at a Child Planning Meeting for all working with the child to plan for how this support may be provided.
- It can be helpful to think about support in terms of meeting a need rather than the number of hours provided.
- The diagnosis itself does not change the needs of the child and therefore is unlikely to change the support provided.

Who will make visual supports for home?

- This can be discussed at your child planning meeting and I will make a note in the summary that you have raised this
- Parents may wish to attend Parent Information Sessions to learn more about visual supports.
- You can attend Boardmaker in Libraries drop ins or go and make resources yourself in the 6 libraries with this software

He behaves really well at school, I think they think we are bad parents – why is he like this?

- It is very common for children with an ASD to cope differently in different settings. They might not present the behaviour as an immediate response to the stress or trigger. They may be responding at home to something that has happened earlier in the day and vice versa.
- Often children with ASD have to work harder than their typical peers to 'get by' at school.
- Good communication between home and school is key to understanding the support needs of each child.
- Increasing predictability in the day, desirability of activities and implementing a clear structure and visual timetable at school can sometimes impact positively on home life. The reverse can also be true.

Getting homework done can be really stressful. What can we do?

- This is a very common area of difficulty for children with an ASD. Communication with school is key. Getting clear written homework instructions can support you to support your child.
- Let the school know if this is taking longer than it should or becoming a source of anxiety. Plan with school staff to reduce expectations and if necessary stop setting homework for the child.

Frequently Asked Questions and Possible Answers

Things that can help are:

- Allowing the child some time to relax on their own immediately after school.
- Having a visual timetable with a plan for time out of school. Put something the child finds motivating immediately after homework on the timetable.
- Using a timer to limit time spent on homework- stop when the timer is up even if work not finished.
- Break the homework into small chunks and spread across the week.

Should my child go to a particular school/ provision?

- We are not able to advise on educational placements
- It is the role of the Educational Psychologist to discuss placements with families.
- We can share the contact details of the EP for the family and can note in the minute that the family would like to discuss this.

Frequently Asked Questions and Possible Answers (Secondary)

What if my child will not accept the diagnosis?

- This is not uncommon.
- You can either do nothing and let time pass or if you feel action is required, contact the diagnosing practitioner to discuss.
- You could discuss this at a Young Person's Planning Meeting—thinking about supportive ways to respond to your child's position being different from yours
- You can try to discuss things that go well and don't go well and what helps/ doesn't help without the need to refer to diagnostic labels.
- If they wish to pursue reassessment or a second opinion about the diagnosis given, contact the diagnosing team.

I am worried my child has a mental health difficulty (anorexia, OCD, self harm, hearing voices, suicidal thoughts)

- In the first instance parents should contact the GP.
- If you already have support from CAMHS you should speak to your link worker.

Questions about Sexual Health

- Discuss your concerns at YPPM.
- This topic is included in the secondary Parent Information Sessions.
- Other Health professionals may also offer support (e.g. Paediatrician)