



Summary of ASD Consultation Activity

September 2015

TABLE OF CONTENTS

Executive summary.....	2
Methodology.....	4
Consultation Events	4
Surveys	5
Community Monitoring and Support Project Data	5
1 – Assessment and Diagnosis.....	6
Pre – referral.....	6
After referral, before first appointment.....	6
Assessment	7
Point of diagnosis	8
Summary of Assessment and Diagnosis	10
2 - Ongoing Support.....	11
Education.....	11
Children.....	11
Adults	12
Transitions	12
Employment.....	13
Emotional and Behaviour Issues.....	13
ASD Specific Issues / Life Skills	14
Housing.....	15
Leisure / Social Activities	15
Support, Advice and Information for Parent / Carers	16
Delivery of Support / Services	17
Summary of Ongoing Support Needs	18

EXECUTIVE SUMMARY

In order to support the Welsh Government Interim ASD Delivery Plan and its work streams a number of surveys and focus group events were undertaken in order to ascertain the issues that individuals with ASD, their carers and family members were currently experiencing. In addition to this data from the ASD Community Monitoring and Support Projects has been utilized within this report. This information will be used to inform the work of the Welsh Government working groups, (including the ASD Strategy Refresh group and ASD Assessment Task and Finish Group), the work of the ASD Development Team and to inform developments as local and regional level.

Parents, carers and individuals with ASD frequently tell us that their support needs are not being met, and this exercise aimed to identify the areas within which gaps in provision remain.

Many parents, carers and individuals with ASD spared their time to share their views with us. However it is worth noting that it is quite clear that individuals are feeling very frustrated by contributing to numerous consultations and surveys and not seeing outcomes from these. Parents / carers and individuals with ASD have been involved in numerous consultation exercises undertaken by Welsh Government, Local ASD Steering groups, voluntary organisations and researchers over the past few years. We now have substantial information about the needs of individuals with ASD and their carers and must seriously consider whether future consultations are really necessary.

Gaps in provision and issues that are experienced are broadly similar for children and adults, and there is a similar pattern of unmet needs reflected across all activities undertaken.

Assessment and diagnosis (children) is clearly an issue in many areas, with many families experiencing difficulties in accessing diagnostic assessment. There are many issues with diagnostic assessment provision, but the major issues impacting on families appear to be:

- Long waiting times
- Lack of information prior to, during and following completion of the diagnostic assessment
- Little or no provision of advice and support at point of, and immediately after, diagnosis

With regard to ongoing support and provision the most frequently reported areas of unmet need across children and adults are:

- Support for emotional / behavioural issues
- Support for ASD specific issues and life skills
- Access to social and leisure opportunities within own community

In addition to these lack of supportive ASD aware education provision was a frequently reported issue for children with ASD and lack of support for employment was a frequently reported as an unmet need for adults.

Parents and carers also report unmet support needs. Again these are consistent across those caring for children and adults, with the most frequently reported being:

- Inability to access advice in a timely manner
- Lack of social activities leading to social isolation
- Lack of training, information and support to manage problems and behaviours

Parents / carers also clearly find ambiguous information, timescales and advice very difficult.

Across all areas of need and all ages, there appear to be three themes emerging:

- Staff within many generic and community services lack the skills and knowledge to support individuals with ASD
- Eligibility criteria for tier 2 and 3 services mean that individuals with higher functioning ASD (and their carers) fall into gaps between mental health and learning disability services and so cannot access emotional, behavioural, low level mental health and life skills support.
- Existing generic community support and services need to be adapted in order to be suitable for many individuals with ASD due to their specific needs.

It should be noted that developments to address many of the issues raised within this consultation are already underway, directed by the ASD Interim Delivery Plan.

METHODOLOGY

CONSULTATION EVENTS

Parents and carers of people with autistic spectrum disorder participated in six focus groups across Wales. Events were held in Haverfordwest, Cwmbran, Neath, Pontypridd, Caerphilly and Shotton, a sixth event planned for Powys was cancelled due to low number of attendees.

For the first three events, the focus groups considered two themes; diagnostic assessment and ongoing provision of support. The final 2 events looked at only the ongoing provision of support theme.

Within the diagnostic assessment theme, attendees were asked to share their experiences of diagnostic assessment and then to consider ideas for a suitable 'Model of a Supportive ASD Diagnostic Pathway'. This theme was divided into the following sub-themes.

- The time between concerns about ASD first raised with a professional, and a referral for an assessment being made
- The time between the referral being made and the first appointment
- The time between first appointment and diagnostic assessments being undertaken
- The diagnostic process
- Feedback from assessment and immediate post diagnostic support

When considering the ongoing provision of support theme, attendees were asked to share their experiences to date and then to consider components of an ideal 'Model of a Supportive Integrative ASD Service'. The support theme was divided into the following sub-themes:

- Education
- Transitions
- Emotional / Behaviour Issues
- Life Skills
- Leisure / Social Activities
- Parent / Carer Support, Advice and Information
- Any other issues

Comments from parents and carers were divided into those caring for a child or an adult with ASD. However, in practice the feedback from the two groups turned out to be broadly similar.

SURVEYS

An online survey for parents and carers of children and adults with ASD was undertaken. The survey looked at broad issues and unmet needs, this survey yielded 857 Responses.

A second online survey, again targeting parents and carers of children and adults with ASD, but specifically targeting experiences of diagnostic assessment was undertaken. There were 192 responses to this survey.

A third online survey was aimed at adults with ASD, and asked individuals with ASD about the support they receive and their wider support needs. There were 130 respondents, to this survey although not all completed all questions.

COMMUNITY MONITORING AND SUPPORT PROJECT DATA

During 2014 project workers within the community monitoring and support projects were asked to collect data around the individuals with ASD, parents / carers and professionals who were using the community monitoring and support projects.

The data was collected over two quarters from projects covering 14 local authority areas. As part of this exercise, project workers were asked to record each service users 'primary need' from a selection of themes. More detailed information about the activity will be outlined in separate report, for the purpose of this report the 'primary need' of unique individuals using the service has been used to provide additional information.

1 – ASSESSMENT AND DIAGNOSIS

The diagnostic assessment process was explored within 4 of the consultation events. A survey was also circulated to parents and carers, there were 192 respondents caring for individuals aged between 2 and 60. There were no representatives at consultation events and only 6% of the responses were from carers of individuals diagnosed in adulthood, therefore this section discusses diagnostic assessment in children and young people only.

Around 50% of survey respondents stated that their child had been diagnosed with another condition in addition to ASD. 17.5% have ADHD, 17.5% have anxiety disorder, 9.2% depression and 2.7% ODD, 2.7% PDAS.

Experiences are separated into stages of the diagnostic assessment process for discussion below.

PRE – REFERRAL

There is a clear lack of understanding about the requirements for referral for a diagnostic assessment amongst parent / carers and potential referrers. A number of parent / carers describe distressing experiences prior to obtaining a referral with many feeling the child had been labelled as 'naughty' or the parent / carer labelled as 'poor parents' or 'neurotic'. Of survey respondents 19% had been referred for assessment within 6 months of concerns first being raised and 22% waited over 4 years. Poor understanding amongst professionals was cited as the reason for this issue.

Of survey respondents 64% experienced issues in obtaining a referral and 42% described these as 'major issues'.

Parents and carers felt they needed more support at this stage and stressed the importance of empathy and understanding from professionals. A frequently heard comment was 'why don't they just listen to us'. They also felt it important that professionals (especially teachers) to be trained in recognising symptoms, and how to refer.

AFTER REFERRAL, BEFORE FIRST APPOINTMENT

The major issue raised in the consultation events was the lengthy waiting times experienced, often following a long period of awaiting a referral to be made. This is not an issue for everyone, 30% of survey respondents waited less than 6 months for the first appointment and 23% waited 6 months to 1 year. However it is clearly an issue for others with 23% waiting 1 to 2 years and 9% waiting over 3 years. The majority of parents and carers felt unsupported during this period, and many were not advised of how long they would have to wait. There were a number of parents who explained that their wait had been extended due to referrals bouncing between CAMHS and Paediatrics, with no clear understanding

of which service had responsibility for undertaking diagnostic assessments. At this point the majority of parents / carers have no support for issues, are unaware of the process and waiting times and do not have a point of contact for directing questions.

16% of survey respondents stated that they received information about the process at point of referral, 49% were able to contact a professional for updates and 37% could access support at this point.

Parent / carers felt that a key worker / point of contact should be given at point of referral alongside information about the process. They felt that an appointment date should be issued, even if this was some months ahead – so that they had a clear idea of how long they would need to wait. Parent / carers felt that this wait should be no longer than 6 months. Parent / carers also felt that there should be a consistent process that was the same for everyone.

ASSESSMENT

The duration of the diagnostic assessment varies greatly with 30% of survey respondents stating this process took less than 6 months, 23% 6 months to 1 year, 18% 1 to 2 years and 14% over 2 years.

19% state their child was diagnosed by a single professional and 28% were seen by 5 or more professionals as part of the assessment process. 43% of respondents state they repeated the same information to different professionals.

Despite NICE guidelines recommending otherwise, parent / carers view the single clinician diagnosis as a useful model, describing issues with waiting times for specific professionals within the process, lost reports or disagreements amongst professionals as the cause of unnecessary delays in obtaining a diagnosis. There were some concerning experiences discussed such as being “diagnosed within 20 minutes when the doctor saw him lining up paperclips”, and “he said he was autistic as soon as we walked in the room”. Parent / carers also appear to be inadvertently misled by the referring professional, frequently reporting experiences such as “[the referrer] told me he was autistic but needed to refer to have it officially”.

Parent / carer also had concerns about describing the child’s behaviour with them present in the room, feeling that they needed to tell the professional the issues but did not feel comfortable being negative in front of the child. Some attendees felt that the assessment process had a ‘male bias’ and had ‘battled’ to obtain a diagnosis for a female child.

Parents felt that information should be sent prior to the first appointment (56% did not receive any information about the process at any point). They felt that appointments should be longer, allowing sufficient time for parent / carers to discuss their concerns. Some felt the first appointment should be for parent / carers only and should not involve the child. There was a general understanding

that assessments should be multi-disciplinary but there were differing views on the role of the educational psychologist (seemingly based on individual's negative or positive experiences). Some felt the discipline needed more prominence within the assessment process and others feeling the role should be limited to educational rather than clinical assessment.

Some participants stressed the need to minimise disruptions to school attendance, a multi-disciplinary assessment taking place on the same day at the same venue was suggested.

Of the survey respondents, 25% rated the assessment process as 'good / very good'; 27% as 'fair' and 44% as 'poor / very poor'.

POINT OF DIAGNOSIS

There were a few issues raised with regard to the way in which the diagnosis was given by professionals. Firstly, many parents were reported to be arriving at the appointment unaware that the assessment had been completed and that they were about to be given a diagnosis. Parent / carers felt this meant they had not had time to prepare emotionally for the diagnosis, nor to prepare questions etc. In one Health Board area parent / carers were not given an appointment, and received their diagnosis via a letter which gave no opportunity for asking questions or receiving information.

The majority of parent / carers describe being issued a diagnosis with no further support / follow up. Coined by one parent as the "diagnosis and a handshake" scenario, this clearly leaves parent / carers feeling anxious and unsupported and does not provide them with the advice and support they require to manage their child.

Some parent / carers were given the diagnosis alongside advice and information at the appointment, for many this was not followed up with any of the information being given in writing for them to peruse later or share with others.

Of our survey respondents 62% received a letter / report stating the diagnosis for 24% this included an outline of the child's strengths and difficulties. 27% received advice / information about ASD; 18% received a referral to other services.

87% were not given advice about how to access support in the future, 13% were directed to parent training programmes.

73% were not given written information about ASD, despite a WG funded guide being developed and issued to local area leads and only 2 of the respondents received the WG funded DVD for parent / carers following diagnosis.

72 % of parent / carers stated they did not receive adequate support at the point of diagnosis and 68% stated that the child they care for did not receive adequate support.

Despite many professionals believing that a diagnosis is not necessary for a child to access support, parent / carers disagree with 91% of respondents believing a diagnosis is necessary. Within the consultation events all parent / carers felt the diagnosis was essential to access services, with educational provision and children with disabilities teams being two commonly cited examples of this.

Parent / carers told us that receiving a diagnosis had other significant benefits that impacted on their daily lives. Many told us that having a diagnosis meant that their children were no longer regarded as 'naughty' and professionals and wider family members were able to understand that the issues were not caused by 'poor parenting'. For some it enabled them to access benefits providing greater financial stability for the family. For many parent / carers knowing that their child did have ASD enabled them to be able to understand them and respond to their behaviour more appropriately. Of our survey respondents, 77% stated that a diagnosis had helped them to understand their child better.

A number of parent / carers felt that professionals wrongly assumed that they were pursuing a diagnosis for their child because of the financial incentives, one poignant quote -"do they really think I would want my kid to have this so I could get a few extra quid in my benefits?"

For some parents / carers being told their child had autism was devastating news whilst other describe relief at getting to the end point of the assessment process.

Parent / carers felt that there were many things that could help improve this stage of the process. All agreed that receiving a diagnosis by letter was inappropriate and all felt that an appointment with the professionals who had contributed to the diagnosis was essential. They felt that being advised of the purpose of this appointment in advance would be very useful, as this would enable them to ensure that all relevant parties were available to attend, to be able to prepare emotionally and also prepare questions they have.

Provision of quality information was also regarded as essential, with parent / carers also stating that a 'profile' of their child would be really useful for them and to share with others. Any information given verbally should also be provided in writing to allow time to re-read or share with others. Parent / carers felt they should be offered a follow up appointment (at around 6 months later) so that they have opportunity to discuss the diagnosis again when they have had time to digest and accept the diagnosis.

Some parent / carers felt that they should be offered annual appointments following diagnosis, so that their child could be regularly reviewed and that parent / carers could receive advice regarding their child as they grow and their needs change.

SUMMARY OF ASSESSMENT AND DIAGNOSIS

Parent / carers experiences of diagnostic assessment vary greatly, although there are positive experiences, 44% of survey respondents describe their experience of the diagnostic process as poor or very poor.

From the consultation events, there appeared to be a correlation between the age of diagnosis and experience, with those whose children were diagnosed under 5 describing a more positive experience. From our survey around 30% of respondents report the person they care for received a diagnosis at aged 5 or under, and 25% described their experience as good / very good.

Despite the numerous issue raised, the key issues causing distress for parents and carers appear to be:

- Long waiting times
- Lack of information prior to, during and following completion of the diagnostic assessment
- Little or no provision of advice and support at point of, and immediately after, diagnosis

The needs of parents and carers discussed in section 3 of this report should also be considered in the context of the diagnostic assessment process.

2 - ONGOING SUPPORT

Experiences and unmet needs in relation to support for children and adults with ASD were discussed at all the consultation events, parents / carers were also asked what they felt services (including any new service) should provide in order for individuals with ASD to be supported.

Two surveys were also undertaken in relation to service provision and support needs. There were 857 responses to the first survey which targeted parents and carers, of these 195 were parent / carers of adults. For the survey targeting adults with ASD, there were 130 respondents, with 92 answering past question 2 and 72 completing the survey in full.

During 2014, a data collection activity within the Community Monitoring and Support projects was undertaken. As part of this activity, the primary needs of users of the service were recorded over a 6 month period. This information has been utilised within this report.

For the purpose of the report, the information has been collated into the areas specifically explored during the consultation events.

EDUCATION

CHILDREN

Concerns were raised in all events in relation to the level of knowledge and skills amongst school staff. Many parents felt that teachers, SENCOs and LSAs did not have a sufficient level of knowledge and understanding to be able to support children with ASD. Concerns about teacher's ability to recognise symptoms of ASD and respond appropriately prior to diagnosis were also raised. Within the survey 38% of parent / carers described teaching staff within primary schools as 'not at all knowledgeable', 19% as 'extremely knowledgeable' and 27% as 'quite knowledgeable'. Teaching staff were one of the professional groups scoring highest as 'not at all knowledgeable' on the survey.

Parent / carers also described difficulties in working cooperatively with school teachers. Many stated they felt judged or patronised by teaching staff and many said they felt that teachers thought they were 'bad parents'. The majority of parents told us that they felt school staff did not listen to them, leading to issues within school that could have been avoided. Many parent / carers described experiences of discussing issues at home with teachers, and receiving a response advising that things were different in school only to find out a later point this is not the case.

Parents / carers also felt that the traditional method of writing school reports that only report positives are not useful because they paint an inaccurate picture of the child. Parents report that this can prevent them from accessing DLA and support services as the reports imply the issues are not pervasive.

Parents and carers felt that all school staff should receive appropriate training in ASD, and that staff should recognise that behaviour is not caused by 'bad parenting'. Some parents also felt that teachers should spend more time listening to parents. They also felt more spaces in specialist units should be available and that schools should accommodate some of the specific issues that children with ASD face, such as sensory issues. Parents felt that support systems such as 'buddy systems' and nurture groups were very useful and that psychological therapies should be accessible within the school.

ADULTS

Concerns about the ability of local colleges to adequately understand and support adults with ASD were raised at the events. However only 19% of parent / carer survey respondents (adult only) cited further / higher education as an unmet need. From the survey of adults with ASD, 22% stated they were in full or part time education with 46% stating they would like support to access education. Of the users of the CMSP (Community Monitoring and Support Projects) 5% were recorded as having education / training as their primary need.

Of the data collected, access to education for adults with ASD was one of the lowest reported 'unmet needs' for adults.

Parents and carers felt that local colleges need more training in and understanding of ASD, but the wider service gap appears to be around support to access education provision in the first instance.

TRANSITIONS

There was a mixed picture of experiences around transitions within the events. There were 2 transition points which appeared to be very difficult for some – primary to secondary, and secondary to adult services.

Some parents described their experiences of transition from primary to secondary as poorly planned, and issues around late decisions around secondary provision appear to be a causative factor.

In relation to transition to adult services, one parent described the period as 'hell for parents' and many stated that very little help was given. Others had more positive experiences.

From the survey 40% of parent / carers state that the individuals they care for had support around transitions.

In relation to transition to adult services, many parents / carers felt that the real issue was not around being unsupported but the fact that there are no services for adults with ASD to transition into.

EMPLOYMENT

Of the survey of adults with ASD respondents, 26% are currently in paid employment and 16% of these receive support whilst 56% would like support in their employment.

50% of respondents stated they have never been in paid employment. 19% were currently receiving support to find employment and 51% would like additional support.

Of the users of the CMSP, 17% were recorded as having employment support as their primary need.

Parent / carers felt that individuals with ASD are unsupported in relation to employment. Whilst the need for more training for employers, jobcentre staff and career advisors was raised, many were clear that the person they care for would need more in depth and ongoing support in order to achieve and sustain employment. Suggestions around greater access to work experience and advice around matching work to the individual strengths of the person with ASD were made. Some parent / carers felt that adapted work environments (longer lunch breaks, quiet work areas etc.) and supportive managers and colleagues were essential for employment to be achievable. In one area, parents felt that adults with ASD should be provided with a support assistant in the work environment, as they had been in school.

EMOTIONAL AND BEHAVIOUR ISSUES

Parents / carers raised many issues regarding a lack of support for emotional and behavioural issues. There is ongoing frustration regarding being unable to access SCAMHS or adult mental health services for support, which is contradicted by frustration about SCAMHS or adult mental health services not providing suitable support for those who have eventually accessed them. Support for individuals with ASD who are experiencing low to moderate level emotional and / or behavioural issues is clearly one of the biggest gaps in support that was identified through consultation events, surveys and CMSP data collection activity. This gap appears to be consistent across the age range. The most frequently reported area where needs were not met from the parent / carer survey was 'emotional issues' with 59% of parent / carers reporting this, a similar percentage (60%) of parent / carers of adults reported this as an area of unmet need.

From the survey of adults with ASD, 90% reported that anxiety prevented them for doing things and 73% reported feeling sad or depressed. 30% of the adult respondents told us they were able to leave the house every day, 42% leave their house twice a week or less (20% less than once a week). 25% report they are receiving support from a CMHT, and 40% have been told they are not eligible for support from a CMHT. 48% of respondents had been referred to a primary mental health team, and 37% had received support from a mental health team.

70% stated that they found it difficult to make appointments with their GP practice and 60% found it difficult to attend appointments. 54% find their GP helpful, 49% stated that they did not feel their GP understood their difficulties.

From the CMSP data collection exercise, around 20% of individuals contacting the service were recorded as having 'emotional / mental health issues' as their primary need which was the third most common reason for contacting the projects.

From discussion at consultation events it appears that eligibility criteria are a barrier to accessing mental health services, with these often set at "ASD with complex needs" or "severe / enduring mental health issues" leaving any children and adults with ASD and lower level emotional issues or behaviour issues ineligible for services. Many parent / carers of children told us that education support does not extend outside of school, and did not provide them with advice about how to manage behaviour at home. Some parent / carers told us that the only support they had was from other parents / carers, who could sometimes offer advice if they had experienced similar issues.

For those who had accessed support from mental health services, there were concerns raised about lack of knowledge of ASD amongst professionals (within the survey 25% of respondents described mental health team staff as 'extremely knowledgeable', 50% as 'quite knowledgeable' and 25% as 'not at all knowledgeable'), being offered medication as the only option of treatment or therapeutic interventions being 'too generic' and not well received by individuals with ASD.

At 4 of the consultation events, the need for emotional support for siblings was raised and identified as a gap.

Participants in the consultation events felt that mental health services should provide crisis support for individuals with ASD, and that individuals should be able to access ASD specific / specialist psychological therapies. They also thought more guidance for parents / carers on behavioural issues should be available. Practical issues, such as the need for a quiet room within schools and clinics were raised, and a frequent request was for sensory integration therapy to be made available. One area raised the need for ABA to be made available and funded locally.

From the survey of adults, 42% stated they would like to be able access counselling/ therapy.

ASD SPECIFIC ISSUES / LIFE SKILLS

Support around ASD specific issues (such as issues with social communication, planning and social skills training) and daily living / life skills was one of the most frequently reported unmet need across children and adults. Within the consultation events, parent / carers told us that support around this was mostly

unavailable, although there were a few parents who described some support being provided via schools. From the parent / carer survey 58% reported support with ASD specific issues such as social skills training as an unmet need (the second most frequently reported unmet need), for parent carers of adults only, 50% reported it as an unmet need and 53% reported support with daily living skills as an unmet need. Around 50% of parent / carers reported they had tried to access social skills support unsuccessfully.

The most frequently reported 'primary need' of users of the CMSP was 'information / advice relating to ASD' (31%) and the second most frequently reported was 'life skills' (25%).

Within the adult survey, respondents were given a list of everyday activities such as shopping and paying bills – overall around 50% of respondents told us that they were unable to undertake these activities without support.

70% of adults with ASD stated that they would like to receive help with their social skills.

Parent / carers feel that more skills training should be available, specific areas highlighted included money management, social skills and independent living skills. From the survey of adults with ASD, when asked which areas they would like support for, the most popular choices were meeting new people, talking on the phone, sports activities and paying bills. The least popular choices were going to a pub or restaurant.

HOUSING

This area was not explored in detail at the consultation events or within the surveys, and was not raised as particular issue by attendees. Of individuals contacting the CMSP, 6% were recorded as having 'housing' issues as their primary need. From the survey of adults with ASD 7% stated they had experienced homelessness, 51% reported they lived with parents, 6% with other family members, 13% lived alone and 2% with other tenants. 26% were parents themselves.

LEISURE / SOCIAL ACTIVITIES

Accessing leisure and social activities was another major gap in provision identified across all consultation activities. Social isolation was cited as a common and significant issue for children and adults with ASD and their carers. Parent / carers felt that staff within non-specialist leisure provision were insufficiently knowledgeable about the needs of individuals with ASD. Many felt that children with ASD needed an appropriate environment to develop social skills, and generic youth clubs / play provision was therefore not suitable. From the parent / carers survey 50% of respondents cited leisure and social activities as an unmet need, with 46% advising they had unsuccessfully sought ASD

leisure activities for the person they care for. Within the survey of adults with ASD accessing sports / leisure activities was the third most frequently selected area respondents would like support with (45%).

Parents and carers feel that more ASD friendly social and sports group would be very helpful, and raised the need for more provision during school holidays, weekends and after school hours. For adults it was felt that these should be matched to ages and interests rather than a 'one size fits all' model. Parent / carers also felt that provision should be available within their own community, rather than the individual having to travel to a specific provision. Many parents felt that activities should match those (though be tailored to meet the needs of individuals with ASD) that other individuals undertake such as using the local pool or accessing local community facilities. They felt that this would stop them feeling 'different', allow them to be able to access independently in the future and provide informal respite for parents and carers. It was suggested that children should be supported more to take part in playground activities and school trips.

SUPPORT, ADVICE AND INFORMATION FOR PARENT / CARERS

In relation to all areas discussed, parent carer support is an area of particular need. Parent / carers describe feeling socially isolated, misunderstood, poorly judged and completely unsupported. They describe themselves as 'battling' to access support or services for the people they care for and feeling exhausted and 'run down' as result. From the survey 44% of parent carers describe themselves as 'highly stressed' and 49% as 'quite stressed'. Many parent / carers attending the events told us they were depressed.

When problems arise, parent / carers tell us they have no way of contacting an appropriate professional for advice, and even services they may be able to access have waiting lists which mean the problem has worsened significantly whilst they are waiting. Whilst many parent / carers related that whilst they found support from other parent / carers via support groups very useful, many explained this was no substitute for professional support.

Many parents have never accessed training in ASD or how best to support their child. From the survey of parent / carers the most frequently reported unmet carer needs were social activities (59%), training (57%) and timely access to advice (49%).

87% of parent / carers want to increase their knowledge of ASD and how to support the individuals they care for, and they would prefer to do this via small group training, from online resources or by talking to a professional.

Around 40% reported 'respite provision' as an unmet need, and this issue was raised at the consultation events. Whilst some parent / carers wanted formal respite care, the majority wanted more informal, shorter breaks from caring (e.g. summer holiday activities, a babysitter to enable an evening out, Saturday clubs).

Many parent / carers of children describe only having respite during school hours, and no break during holidays or on weekends.

From wider discussions at the consultation events it is apparent that parents / carers of individuals with ASD find ambiguous advice, service provision and timescales very difficult. Parent / carers clearly need:

- more clarity about what services are available, what they can offer and their eligibility criteria
- a plan of care which is appropriately directive and that they are able to follow within their daily lives and is regularly reviewed to take into account changes and developmental stages
- to have discussions / advice/ processes supported by written information
- to be provided with resources to help them (e.g. picture cards, home school diaries, profiles), rather than being told to seek them out themselves.
- an appropriate method of sharing and gaining information from those involved in their child's care (home school diaries were cited as useful, but only when used regularly and not just reporting positives)
- training at an early point, and at key developmental stages - regardless of the age at which the person they care for is diagnosed.
- To be able to access advice in a timely manner, and to be advised of how and when they can access this.

DELIVERY OF SUPPORT / SERVICES

Parents / carers were clear that they would prefer support from a service with specialist knowledge of ASD, 63% of survey respondents chose 'specialist ASD service' this as their preferred model for delivery of support. For adults with ASD, it is important for services to be delivered locally with 71% stating they would like services delivered in their own community and 68% saying they would like support in their home. For the adult respondents, the models with the least number choosing them as a preference were 'group training' and 'telephone support'.

Within the consultation events, lack of joined up services and information sharing were raised as issues and parent / carers feel that any support service should work with others involved in the individuals care and also ensure information is shared with all involved (especially parents / carers).

SUMMARY OF ONGOING SUPPORT NEEDS

Unmet support needs appear to be broadly similar for children and adults and their parents and carers.

The most frequently reported areas of unmet need are the same for children and adults:

- Support for emotional / behavioural issues
- Support for ASD specific issues and life skills
- Access to social and leisure opportunities within own community

For children, appropriate educational provision was also a frequently reported unmet need and for adults, support to access employment was a frequently reported unmet need.

There are clear themes across all areas of need - the need for further development of knowledge and skills within generic services and the gap in service provision for those children and adults with ASD who do not meet the eligibility criteria for mental health or learning disability services.

Parents and carers also feel that generic community services need to be adapted for individuals with ASD to successfully utilize them.

The unmet needs of parents and carers are again the same for parent / carers of children and adults, and many parents / carers report feeling stressed and socially isolated. Many want support and advice to be able to support the person they care for in the absence of professional support.