1.0 Introduction
Somerset County Council (SCC) is currently in the process of planning future services for children and young people with an autism spectrum condition and/or communication need.

In January 2014 a survey was distributed for parents/carers, children and young people with an autism spectrum condition and schools. Children, young people and parents/carers have a right to comment on services they receive and tell SCC what is important to them and this must be given due weight (United Nations Convention on the Rights of the Child, ratified by the UK in 1991).

Following on from the opportunity for children, young people, parents/carers and schools to tell the council what is important to people growing up in Somerset with autism, SCC wished to look at more detail and give people a chance to reflect on their experience of and impact of autism services and mainstream services and consider outcomes.

Somerset County Council want to listen to service users and learn from service users, and wherever possible SCC want to reflect what service users want. So Somerset County Council asked Compass Disability Network to approach young people aged 18-25 who may be interested in sharing their views to provide feedback which would inform the Special Education Needs (SEN) review and Somerset Autism Strategy.

2.0 Methodology
As it was identified that many young people may be hard to reach, it was agreed that the best way to consult and obtain information would be to carry out one to one interviews in locations and settings that suited the individuals.

Outline topics for discussion were provided by Somerset County Council and questions were prepared by Compass Disability Network which would form the basis of the discussions.

Topics included;

- Education – getting the appropriate support at school and college and progressing.
- Social interaction / Life after school and Emotional Support
- Independent Living
- Family Life
- Work – preparation and support
- Information and Advice

Contacts for specific organisations and supported housing providers were provided by Somerset County Council.

Publicity information was distributed by Compass Disability Network to the following organisations;

South Somerset Mind
Somerset Parent Carer Forum
Knightstone Housing
YMCA Somerset Coast
Taunton Association for Homeless
Mendip YMCA
Somerset Partnership NHS Foundation Trust
Rethink
South West Independence Ltd
Taunton Aspergers Group
Autism Somerset
Autism Wessex
Somerset Advocacy
NAS – Local Branch Office
FE Colleges – (Strode/Bridgwater/Yeovil)
Lufton Mencap College
Foxes Academy
Fiveways School
Selworthy School

In addition to this information was publicised on the Compass Disability Services Facebook page and the following other facebook pages; Compass Carers, Taunton Somerset, NAS, Autism Somerset, South West-Act now for Autism.

In total 5 individuals came forward to express an interest in getting involved.

Once interviews had taken place some individuals offered to speak to friends and acquaintances to get involved, however it was not possible to pursue this due to timescales involved.
Interviews were carried out in settings as agreed with individuals and included colleges, work place, coffee shops and own home. A parent also provided input at one interview.

Following each interview, individuals were given a letter confirming how the information discussed would be used and that all information would be anonymous. Compass Disability agreed to send individuals a copy of the final report.

3.0 Key Findings
Appendix One provides detailed information from each interview which we would invite you to read. However we have provided below a summary of key findings from the discussions;

School
- Early diagnosis is essential and often the key to receiving support which aids learning.
- There is a need for increased awareness of teachers and pupils to ensure that students receive the support they need and that others are aware of the condition to prevent bullying.
- Problems can occur in secondary school when supply teachers provide cover and do not necessarily understand an individual’s condition. A flag in the register was suggested as a good idea to explain that an individual may need space or somewhere to go to.
- Surroundings in school are important – one person said that out of bound areas were not always clear. Having a quiet place to go with learning support helps some with focus. Another commented that it would be good to have a place to go without question.
- Bullying was something that had been experienced by all individuals to different degrees in primary/secondary school. An assembly to provide information and make people aware of conditions such as Autism would help. One person actually decided to do this to inform others and found this helped. Posters around the school would also be a good idea.
- Schools have been helpful to sort issues with bullying in some instances but not always in others. It is clearly important that policies cover mental health conditions and other impairments that are not always visible.
- Programmes such as ‘Linx’ help to prepare individuals for college and work well. Visits to college (taster days) also helped and activities at school such as going into town.
- Mentors would be a good idea to support individuals in transition and going through exams etc. at school. One person had a
positive experience with a Mentor at secondary school provided by a local Christian group.

**College / Further Education**
- Changes to timetables in some cases cause confusion when individuals start college and can cause anxieties. Changes to timetables were suggested by one person to allow more time for practical work. Knowing what you are doing each week is very important in college.
- All individuals engaged had attended Further Education colleges. Some received support straight away; others did not receive until later – one year into course. Once support was provided it helped an individual with their course, it meant they could go into a separate room which was helpful.
- There is a need for continuity of information on an individual’s needs from school to college to enable support to be available promptly and be responsive to the needs of the individual. One parent noted a difference in communication from secondary school to college which was not as consistent.
- Most liked the social aspects of college and the environment to have their own space.

**Social Interaction / Emotional Support**
- A contact / organisation or person to speak to about problems/dealing with tough decisions was noted as something which would be helpful.
- Counselling is something that has helped one individual process things particularly as it is with someone who is emotionally detached.
- Emotional support was noted as something which would be helpful as well as personal development courses to help progression e.g. Decision Making, Assertiveness, Relevant Courses.
- Youth /Support Groups and other activities have been attended by many of the individuals spoken to and often provided a link to other friends or voluntary work however these are limited in number. An online Forum was another way one person met a friend.
- Parents have provided a consistent support to most young people. Some feel more able to manage their own finances than others and would appreciate any support in this area.
- A mentor for people when they reach further education or working age would also be helpful to suggest places to go or things to try.
• Those that were working had found some part-time and voluntary work themselves or had been approached by existing places they were involved with.
• There is a need for support when an individual approaches leaving college and more information about voluntary schemes such as 'Project Search' which may help an individual.
• Concerns over how the Jobcentre work with people with autism spectrum conditions and a lack of other employment support seems to be available.

Advice and Information
• General information about autism services and support needs to be more available. Most individuals did not know of any local contacts apart from the social groups they may be involved with, however they are limited.
• One person was in contact with a local autism charity which they found helpful.
• Information for parents is important as young people reach adulthood so that they can continue to provide support and guidance. Where higher needs may be identified parents and the individual need to know what financial support or help is available approaching or after the age of 25.

4.0 Conclusion

Due to time constraints involved we were only able to capture a small sample of young people’s views each with varying experiences.

Through discussions with the young people and discussions with parents outside of the interview it was felt that the following points were worth consideration;

Personalisation in Somerset has a long way to go to meet the needs of young people with an autism spectrum condition. When Parent Support Workers are no longer in place to help with information they are missed. Intervention before crisis point is key.

In order to fully appreciate the needs of young people with an autism spectrum condition there needs to be an ongoing dialogue and consultation with families and individuals.

There also needs to more awareness and publication of organisations in Somerset that can provide suitable support or help.
Appendix One

Notes from Interviews

Interview 1 - Male aged 21 Studying at College Level 3

At School

Enjoyed school but not as much as college. At College you get treated as an adult.

Had one to one learning support at school that helped to answer any questions they had and explained if they didn’t understand and demonstrate. As a visual learner it helped to show things.

Were held back a year in primary school, in secondary school felt you were being treated younger than they were.

What else could have been to help at school? Out of bounds areas weren’t always clear – it is good to know where boundaries are. An assembly for pupils to increase awareness of autism and other disabilities would have been helpful.

Experienced bullying – because others didn’t understand condition. Often waited for time to pass before saying something about bullying, and often mentioned after it happened a few times as didn’t want to keep raising it. Wasn’t physically bullied but felt like an outsider. Would often look at those without additional needs and see how to be like them.

General policies about bullies could be more specific to disability so that people don’t judge too quickly.

To prepare for college went on the Linx programme having taster days. 1 day per week to college, cooking and life skills, helped to have others from same school and learning support present.

School encouraged to use own initiative and not be reliant on others.

At College

Receives help with Learning Support Assistant in lessons and support from Learning Support Tutor once a week.

Allowed own space which is different to school. Can work at own pace, and move on when ready.
At the start of year the timetable gets changed around which can be confusing. Had to ask reason for changes. Wasn’t told timetable had changed – was 15 minutes or so late for lesson.

Parents evening / trips information could be sent more in advance

College has opened eyes to world of work. Skills obtained at school not as life based.

Future plans – would like to work in IT software industry. Hopes to get advice in following year about what to do after college.

Regular progression talks help to set short term targets.

When left school questioned change between school and college, had some worries but Linx course helped.

Normally goes about with mum or few friends and goes to familiar places.

Not so much concerned about being bullied now – occasionally in some social situations.

Buying bus tickets worry about people being impatient/being shouted at.

Want to be treated as everyone else. People can be patronising.

Goes to park – meets with friends and town centre.
Has been more social since being at college.
Goes to Gym once a week, does own thing and staff always friendly,
Mum helps with membership.
Like having own space.

**Support**

Support received from parents. Had Social Worker when under 18 and some respite when younger, needed less support when older.

Friends without disabilities mostly, have friends from courses, some do have autism.

Would be good to have a number to speak to about any problems, new social clubs, family issues, dealing with tough decisions.

**Living Independently**
Mum helps with managing money, would like to learn about it more often.

Some decisions he makes himself, some speak to mum and dad.

Gets enough support to make own decisions. Sometimes feel anxious when things change (bigger things).

Mum supervises cooking, before starting asks for reassurance.

Likes to get lots of information before doing something that may involve risks.

Worry what other people think because doesn’t like to get a negative impression.

Does activities with Mum and Dad such as cinema, theatre, museum, London. Has done voluntary work and enjoyed.

Looking for work experience – tutor helping, spoken to Work Academy and going back, and sent CV to some companies.

Worries – wants people to be understanding and respectful and happy in work.

Likes where he lives – would be good to live somewhere on a bus route which would give more independence. Relies on others, feels wants a bit more independence.

Might consider buying or renting flat in future.

Mum said would be happy for him to move, wants to be more confident before and complete college.

Mum gets info about Autism and Dyspraxia.

Don’t usually get information but would be useful.


**Interview 2 Male aged 18 Studying at College Level 1**

**School**

Primary not brilliant, some years better than others.

Sometimes got helped when needed but not always. Early years when needed.
Learning Support – Year 7 & 8 had different ones.

If didn’t understand and weren’t sure would explain in detail.

What LSA’s did was enough at the time.

Year 10 – careers person guided them. Someone who understood disabilities.

School Links programme helped to have a go at chosen course which was more practical, became more independent.

When reported wrong action (bullying), issue may not have always been addressed. Worried about escalation if reported.

**College**

Received help at college – learning facilitator around theory work, sometimes guidance from lecturer, support when theory lessons take place. Help to look over and help to work through and clarify, help to come to right answer.

What college do to make things better – change timetable to allow for longer time for practical work.

Helping to become more independent – feels now knows where to go to get equipment etc.

Wants to go and do work on building sites and apprenticeship, wants to learn all skills. Would be helpful to get qualifications and apprenticeship.

A bit of help may be useful for finding apprenticeships.

Felt it was nice to leave school and quite easy.
No concerns about going out on own.
No concerns about being bullied experienced a bit of teasing at school.

A good social life means having a good group of friends who can support you.

Is not so keen on sport.
Gets a bit of support from mum, tutor, some friends.

Other services that may help? Understanding people a bit more – how to help and listen to that person.

Manages own money, wouldn’t go to bank on own, would want support. Might need a bit of help budgeting.

Makes own decisions, would tell parents if planning something soon.

Yes, risks don’t stop them doing the things they want.

Would be very brief with people he does not know.

Sometimes does things with family, doesn’t do a lot with friends.

Does voluntary work in charity shop, who are aware of condition, sometimes they forget, and they help with what he needs.

Not looking for job.

Lives with parents, quite happy.

 Doesn't get specific information.
Part of disability group that parents found out about support group.
Newspaper/internet would use to find out information.
Might need help looking for it.

Interview 3 – Male Aged 18 Studying Foundation level Course at College

School
Experience was not so good at junior school, third year was better when support needs were put in place after diagnosis. Diagnosis at aged 9 also has receptive language disorder.

First year at senior school felt in danger, experienced bullying for 5 years. Have problems with anger management. Felt school was sometimes good, sometimes not so good.
Did an assembly in front of other pupils to raise awareness of condition.

School dealt with problems but experience was up and down.

Had Learning Support at Primary, different people provided from a group of support. Had some lessons separate.

Some sessions took place with separate discussions with students that were causing problems which helped.

SENCO at school was very supportive and parents were in regular contact and had lists of preferences etc.

Transition to college – had visits to college when at school. School also tried to help by taking into town to buy things, going to buy ingredients etc. Also went to Hub as part of curriculum.

Suggestion to increase awareness of condition with pupils and teachers. Sensitivities exist when people make jokes etc. Posters about bullying and the assembly helped.

College
Sometimes get help at college, small classes specialist help.

Not as good as communicating with parents as secondary school – when discussions take place this helps to improve things.

Special needs at college feel had a babysitter, sometimes feel like a barrier.

Socialising important to him was put in different parts of school.

Understanding is very important from others – often blames himself.

College helps to become independent bit by bit. Independent living Skills – provide help with cooking.

Is on a 2 year course and interested in ‘Project Search’.
Not easy to adjust after leaving school – had a good network at secondary.

Does go out on own but does sometime get concerned, still gets bullied verbally when walking to and from college.

Like to do things that interest him – films / film stars.

Goes out to meet people in town. Would be good to meet people at organised times. Sometimes get to do activities with friends.

Likes to use college gym on own.

Gets support from parents, not so much from friends. Attends local Youth Club.

Would be good to have a mentor own age to go somewhere with. Likes to socialise with own age.

Gets some help from mum and college to manage money but finds it hard to do.

Makes own decisions sometimes with help and gets to do the things he wants. Manages to do things that involve some risk.

Sometimes feels anxious with people he doesn’t know.

Goes out with family and visits other members of family.

Would like to run a business in future.

Has worked with National Charity on a specific project.

Does work experience at local primary school one day a week – admin /help with reading etc. Loves working with young children. Had to find this out himself independent to college.

Is looking for paid work, mum has helped to fill in forms for applications.
Living at home with parents and family.

Not aware of anything locally about Autism.

Has lots of questions about future entitlements, miss not having parent support worker to help with information, what about residential colleges etc.? Need for employment support.

Aware of one group locally set up and run by own parent.

Concerns about after the age of 25 when support stops.

**Interview 4 – Male aged 28 working Part-Time**

**School**
Did enjoy being at school on face of it. Taking into account difficulties he had, enjoyed the structure and learning.

Looking back was grateful. Has Asperger’s and experienced bullying throughout education.

Due to emotional difficulties – found hard to process things in adolescence and grades altered as a result.

Did not have many friends, spent time in library. Now older has 2 or 3 friends still in touch with. Did feel isolated at time.

Received diagnosis at aged 13/14 before this was considered to have special needs (speech and communication problems)

Year 10 was assessed and received support for speech problems. Since diagnosis things were explained and were able to find out more things about condition, continue to find out now.

The Special Education Needs Department provided help twice a week with one to one support out of class.
Happy with learning and getting into a book. Found help that received for speech problems helpful. Teachers were aware of condition but some didn’t understand.

Earlier diagnosis would have been more helpful. School could have helped more with bullying. Mum took out of school at one point because of it.

Need for more understanding of mental health problems at secondary school.

Had 1 day visit to college which was helpful for transition. Did career studies to help prepare.

Had a mentor in Year 11 provided by a local Christian group which helped – related to their interests, someone to offload to and talk about homework with, took to social group, this was provided by school.

**College**

Eventually got help needed towards end of first year, someone from student support made themselves known to them. Once knew about it use it more which helped with grades. Helped focus and keep on track. Took into separate room which was helpful.

Saw a poster in one of the learning rooms for a local charity mental health group and decided to attend.

Would have been helpful for school to communicate to college support needed so that this could have been obtained sooner.

Good to have someone to suggest changes to routine.

College meant had to learn to manage own time – had more spare time, needed to learn how to manage this. College more flexible than school. Helps to have structure which was same every week – knowing what you are doing is important.
When at college wanted to work on railways, now shifted to working more with young people and mental health. Through experience feels can offer a lot.

Speaks to counsellor on regular basis which helps – someone emotionally detached

Personal Development courses would be helpful; Decision making, Assertiveness, Relevant courses.

Found after school not so easy to adjust, after college struggled to find work for 4 years.

Generally feel OK with being on own, sometimes want to just stay in.

Always wary of comments from others, now older not so bothered about bullying.

Experienced bullying at school and family member (psychological).

A few years ago was more on own, now happy with friends – has small numbers but good friends. Feel generally happy now but has taken many years. Has found friends through support groups and music band. Also goes to football group once a week which he enjoys.

Would like to get back into swimming - not part of routine at the moment. A friend took them once, when a friend goes with them it is easier to do.

Sometimes want to shut themselves away at home on Xbox.

Friends provide support network and dad and brother try to support but not always easy for them. Let them do what they want and are there when needed.

Attends drop-in social group for condition once a week. Does voluntary work with music at a local adult learning centre.

Generally happy with managing own money. Would find money advice useful.
Makes a lot of decisions on own. Needs a lot of time to make critical decisions such as jobs and would like help with – friends often say ‘up to you’.

**Accessing Information**
Is aware of places such as Citizens Advice but you do not know the people.
Had a bad experience with a Job Broker at the Job Centre when on Job Seekers allowance, insisted on applying for 3 jobs per week and didn’t understand the difficulties and the condition. Made them feel ‘rubbish’ said that ‘lots of others have Asperger’s can do this’. This was a few years ago and think it may be better now.

Is sensible making decisions that involve risks, will minimise risks if think there are risks involved wouldn’t do for something.

Ok with people that he doesn’t know when prepared, not favourite thing to do. Can get nervous but keeps trying to overcome this.

Does some things with family every few months, will sometimes back out if doesn’t like the sound of something. Likes taking videos of trains. Family know what he likes to do.

Goes on trips with music band, something he would have not done years ago and now does what friends want as well as him.
Likes hanging out with friends, friends are supportive, finds it helps to be around others with mental health problems.

Has 3 part-time jobs, doing cleaning and youth project work. Had ‘grief’ for not working when younger and thinks about what other think about those that do not work. Used internet to find one job and found out about others through youth groups attended.

Employers are aware of condition, one wasn’t aware initially but is now and this helps them to understand in certain situations.

Happy to work on own in one job. The project he is working on is due to come to an end soon and has been looking at other jobs; current
employer has been supportive and thinks that job centre may help at some stage.

Not discontented where he lives with family, likes the idea of having own space and has considered living on own but has to consider financial implications.

Has been to a couple of housing information drop-ins at local charities / housing associations and would like to look at but needs more income to do this.

Knows where to go to get information.

Local Autism Charity is very helpful and familiar.

Mostly receive information from the internet and other groups that he attends. He gives information to family members that he lives with.

Sometimes prompts / suggestions from others provide help to try new groups or places to go to.

Feels is own individual person but recognises Asperger’s behaviours in others (there is a cross over – not everyone the same).

Interview 5 – Male aged 23 working full time

School
Kind of enjoyed being at school. Form tutor and head of year understood him, a few teachers understood and he could go to. Had a Learning Assistant in Year 6, receive actual diagnosis (Asperger’s) in Year 7/8. Experience at Junior School not so good, teachers didn’t understand. One teacher tried to get him to face back of class, another tried a reward system which didn’t work. One tutor called him ‘funny boy’.

Experienced bullying at school, felt was an easy target as used to flip easily, experienced fights and name calling.
Had help at secondary school and was excused from one lesson which found hard, sent to a room with a Learning Support Assistant. LSA’s helped with other work and provided some help in classroom to keep focussed. In general the school wasn’t too bad. However felt that supply teachers weren’t aware of condition and didn’t know situation.

Would be good to have a place to go without question. Often teacher would keep you there and get you more wound up. One stood in way of door once which caused an issue. A flag in the register would be helpful so supply teachers are aware – to allow a student to go somewhere quiet when they needed to.

Towards the end of year 11 had a bit more freedom, went to open evenings to find out about things, and liked the thought of doing something practical as well as reading.

Don’t like being labelled and doesn’t put on job applications. Many people do not understand and make him feel he can’t say he has autism.

**College**
Offered help in the way of Learning Support but he decided he did not need it.
Generally felt coped OK, more freedom at college which he preferred and treated at similar level as adult. Felt more relaxed and not treated as child.

Had one issue with another student who said lots of things which built up but this was dealt with by a teacher.

**Work**
Has been employed for 5 years working full time as a technician at a college.
Worked part-time in MacDonald’s when at college studying, wanted to work in kitchen to avoid talking to people but was put on tills straight away, found this benefitted him to overcome some difficulties working with people.

On Level 3 course at college was offered some temporary hours working in college and also worked at MacDonald’s.
Employers are aware of condition and most colleagues know.

Does not know of future plans at moment.

Found best friend on internet Forum who has ADHD, meets with friends who have similar interests.

Lives at home with family.

Decided to stop DLA himself as was happy to manage money. Makes own decisions.

Finds own emotions difficult to deal sometimes, maybe would help to speak to someone about how to deal with emotions.

Hates going into town (pubs etc.) as busy when you are nudged in pubs. Would rather go somewhere quiet.

Found it easy to tip over edge at school but find now finds it easier to deal with.

Gets to do things with family meeting up with other members nice to do. Goes camping with friends sometimes.

Has looked at moving out of home but bills etc., have prevented this. Has a garage to go to escape.

**Information**

Never really looked at, goes online for information, reads an odd article about condition and looks at other views occasionally.