

Autism - Transition to Adulthood

A report by Healthwatch Isle of Wight

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ASD is a particularly complex condition and provided a steep learning curve for the Outreach and Engagement Officer to understand how it can affect individuals, the multi-faceted and changing health and social care agenda around it also proved a challenging to comprehend.

Healthwatch Isle of Wight is therefore, particularly grateful to all those professionals who spared the time to meet with us, particularly, Lorraine Shotter - chair of Parents Voice, who provided invaluable advice and signposting throughout the process.

In addition, we are grateful to professionals and volunteers within both the statutory and voluntary sectors who gave invaluable insight into the area.

Claire Collins, the Autism Advocate, not only provided her expertise, but also facilitated our two workshops for which we are immensely grateful.

We are also extremely grateful to those voluntary groups that allowed us to visit and speak with their service users, parents and carers. Parents and Carers who volunteered their time to share their experiences and attended our workshops, met with us face to face or discussed issues on the phone and completed the on-line survey.



Introduction



Healthwatch is an independent consumer champion created to gather and represent the views of the public on health and social care. It gives people a powerful voice locally and nationally.

Healthwatch plays a role at both national and local level and will make sure that the views of the public and people who use services are taken into account. At a local level, Healthwatch Isle of Wight is helping Islanders get the best out of their local health and care services. Whether it's improving them today or helping to shape them for tomorrow.

During 2014 Healthwatch Isle of Wight received a strong set of feedback regarding the lack of services available for young people with Autism going through the transition from Children's Services to Adult Services, as result 'Autism - Transition to adulthood' became a priority identified for further research.

Autism is a spectrum disorder, with it affecting individuals in differing ways and differing degrees. NHS Choices describes Autism Spectrum Disorder (ASD) as; 'a condition that affects social interaction, communication, interests and behaviour. It includes Asperger syndrome and childhood autism. In the UK it is estimated that up to 1: 100 has ASD, 700,000 people. There is no cure but a wide range of treatments - including education and behaviour support - can help people with the condition.

On the Isle of Wight ASD is known locally in some user groups not as 'Autism Spectrum Disorder', but as '*Autism Spectrum Diagnosis*', removing connotations of people with Autism somehow being flawed. Healthwatch Isle of Wight has also adopted this acronym so when using ASD, we mean *Autism Spectrum Diagnosis*.

Transition from children's services to adult services and preparation for adulthood is incredibly important for children and young people with ASD.

The HM Government Autism Strategy (March 2015) describes transition as; 'Transition to adulthood is a crucial stage in the lives of all young people, and a time when those with autism may face particular challenges. Good transition support for children and young people with autism can have a profound impact on their ability to reach their potential, through access to further learning or training, employment and independent living.

Co-operation between the relevant authorities is crucial if the person is to fulfil their potential. Local authority children's and adult services, children's health services and social care all need to play a part.

In 2009 the government introduced the Autism Act which was the first piece of legislation developed to serve the needs of individuals with a specific condition. In March 2010 the Government produced an adult autism strategy: "Fulfilling and rewarding lives: the strategy for adults with autism in England." This sets out the strategy for meeting the needs of adults on the autism strategy in England by improving the provision of relevant services by local authorities and the NHS.

This strategy was updated in 2014 and has a clear vision that: "All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents."



Methodology:



In common with previous Healthwatch Isle of Wight themes, a community engagement approach was adopted to find out more about the experiences of people with ASD, their parents and carers.

A community engagement approach was adopted for this work-plan theme as it is recognised as an empowering method to give service users a voice in how services are shaped and delivered.

Popay 2006, defines Community Engagement as the process of getting communities involved in decisions that affect them. This includes the planning, development and management of services, as well as activities which aim to improve health or reduce health inequalities.

Healthwatch Isle of Wight believes that the principles outlined in the National Institute of Clinical Excellence (NICE) Public Health Guidance PH9 (2008) are utilised through its outreach and engagement programme.

Key points of this include:

- 'utilise local people's experiential knowledge to design or improve services, leading to more appropriate, effective, cost-effective and sustainable services'
- 'build more trust in government bodies by improving accountability and democratic renewal'...
- 'contribute to developing and sustaining social capital'
- 'Learn from and build on previous or existing activities and local people's experiences to engage them, using existing community networks and infrastructures'.

NICE defines Community development as 'about building active and sustainable communities based on social justice, mutual respect, participation, equality, learning and cooperation. It involves changing power structures to remove the barriers that prevent people from participating in the issues that affect their lives. This is vital to the successful operation of Healthwatch Isle of Wight.

During the investigation of previous themes, the local knowledge and extensive contacts of the Healthwatch Outreach and Engagement Officer who combines this role with that of co-ordination of the Isle of Wight Voluntary Sector Forum have proved effective in meeting with communities and those that are defined 'hard to reach'. However, as a relatively small cohort of people on the Island, this method did not prove to be as effective, hence other strategies were employed.

A survey monkey questionnaire for people with ASD and their parents and carers was designed, tested and circulated via conventional methods and social media.

We also asked other relevant organisations to circulate to their service users.

Healthwatch Isle of Wight is grateful to all those organisations who assisted in this process.

Meetings with professionals working with people with ASD, their parents and carers were held to discuss ways and strategies of reaching the identified group, and to understand more about the processes, services and difficulties encountered by the identified group.

Healthwatch Isle of Wight is grateful to all those professionals who spared the time to meet with us, particularly, Lorraine Shotter - chair of Parents Voice, who provided invaluable advice and signposting throughout the process.

In addition, Claire Collins the Autism Advocate was engaged to deliver two workshops to understand more about the experiences of those going through transition, their parents and carers.

4. Do you know who needs to make each thing in your plan happen?
Please put a tick next to just 1 answer
- Yes
 - No
 - There is no plan
5. Do you know when things are meant to happen?
Please put a tick next to just 1 answer
- Yes
 - No
 - There is no plan
6. Did the people who wrote the plan ask for your ideas to help write it?
Please put a tick next to just 1 answer
- Yes
 - No
 - There is no plan
7. Do you know if your parents or carers were asked if they wanted help to look after you?
Please put a tick next to just 1 answer



Figure 1 – Easy Read Autism Survey

National Policy Context

Think Autism: an update to the strategy for adults with autism in England

'I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies'.

According to National Autistic Society (NAS) research it is recognised by SENCOs that a child's disabilities may increase through the transition period. NAS research also suggests 71% of young people with autism have at least 1 mental health problem and 40% have 2 or more mental health problems.

In March 2015 statutory guidance for Local Authorities and NHS organisations was published to support the implementation of the Adult Autism Strategy. It includes the following statement;

Transition to adulthood is a crucial stage in the lives of all young people, and a time when those with autism may face particular challenges. Good transition support for children and young people with autism can have a profound impact on their ability to reach their potential, through access to further learning or training, employment and independent living. Co-operation between the relevant authorities is crucial if the person is to fulfil their potential.

Local authority children's and adult services, children's health services and social care all need to play a part.

However, local authorities, NHS bodies and Foundation Trusts need to recognise that not all young people with autism will have Education, Health and Care Plans (EHCP). Receiving support in making the transition to adulthood, and accessing appropriate services as an adult should not be dependent having an EHC plan. Indeed the Care and Support statutory guidance, issued under the Care Act, sets out that local authorities should consider how they can identify young people who are not receiving children's services who are likely to have care and support needs as an adult.

The guidance identifies young people with autism whose needs have been largely met by their educational institution as an example. Not everyone with autism will have an EHC plan, but this should not prevent planning for supporting the transition from children's, to adult services.

This guidance also makes reference to United Nations Rights of the Child, in particular articles 12 and 13, Article 12 (Respect for the views of the child): When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account.

This does not mean that children can now tell their parents what to do.

This Convention encourages adults to listen to the opinions of children and involve them in decision-making-- not give children authority over adults. Article 12 does not interfere with parents' right and responsibility to express their views on matters affecting their children.

Moreover, the Convention recognizes that the level of a child's participation in decisions must be appropriate to the child's level of maturity. Children's ability to form and express their opinions develops with age and most adults will naturally give the views of teenager's greater weight than those of a pre-schooler, whether in family, legal or administrative decisions.

Article 12 (Respect for the views of the child): When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account.

Article 13 (Freedom of expression): Children have the right to get and share information, as long as the information is not damaging to them or others. In exercising the right to freedom of expression, children have the responsibility to also respect the rights, freedoms and reputations of others. The freedom of expression includes the right to share information in any way they choose, including by talking, drawing or writing.



Local Policy Context

The Isle of Wight Local Offer describes 'Preparation for Adulthood' as an important part of a young person's transition to adulthood is his/her path through education and into training and employment.

During this time, there will be a number of decisions to be made about the future. This includes whether to continue in school, go to college, undertake training or look for employment. All young people face major changes as they move from being teenagers to becoming adults and need to make important decisions about their future.

This change can be more complicated for young people with learning difficulties and/or disabilities as they are often involved with a number of support agencies. Transition planning is about co-ordinating and preparing for the future and this involves families and services working together.



Planning starts well in advance of leaving school to make sure that each young person's needs and choices are fully explored.

The Isle of Wight Joint Strategy for Children, Young People and Adults with Autism Spectrum Condition 2014-19 covers transition in Chapter 6.

Key points include that:

- There is often a need for support from more than one organisation, this means that the focus should be on the needs of the individual, together with listening to their parents and carers.
- Transition should be planned and timely, not rushed or last minute.
- There will be more awareness raising with providers of further education and employers.
- A clear person centred transition pathway to be developed with effective signposting for those who do not meet the eligibility criteria.

Transition

It's a transition every day just getting him from home to school'

Healthwatch Isle of Wight carried out a number of interviews with parents and carers, some of their children were at the beginning of transition Y9 with others having children up to their late twenties who had recently completed the process.

We also launched a survey via survey monkey and invited parents to give more detailed views via face to face meetings or telephone call as part of this. In addition, with the support of Claire Collins we held two workshops inviting parents and carers together with young people with ASD to attend and give their views.

Unlike previous work-plan topics we received a relatively small number of responses and few attended the workshops. We wished to understand the reasons behind this so talked to those who did take part and professionals in the voluntary sector supporting them.

A key point was that parents/carers and service users alike were unfamiliar with the term transition, hence could not see its relevance to them.

The four other key points of note were that in some circumstances parents had played an active role in sharing their views for the IW Joint Strategy so could be classed as having 'consultation fatigue'.

Another issue identified was that parents/carers were exhausted by the 'day to day' of care of their loved one that they could not spare the time to take part.

Finally, and in common with other Healthwatch themes is the fear of being identified. Although Healthwatch respects and protects the confidentiality of all those who share their views with us, in sharing their stories and experiences.

As there are such small numbers involved, it can be possible to identify individuals. Individuals may also fear this, and it can lead to reluctance to share information. As many are afraid that this can reflect on future service delivery for themselves and their loved ones. This issue is true of any issue that Healthwatch examines.

Our survey which ran from February through to late March elicited 12 responses from parents and carers and 8 for the 'easy read' version for service users.

Our workshops despite being well publicised on local conventional media and specialist social media had just three attendees in all 2 at the evening session on 18th March and just one in the day time session on 25 March.

However, these small numbers gave us the opportunity to examine in detail the issues facing these parents and carers, and their loved ones.

We designed the survey questions using best practice from the NAS website on what ‘good’ transition should look like. See annex 1 for copies of the survey for parents and carers and the easy read version for service users. We were mindful that a survey only gives opportunity to answer ‘closed’ questions so gave ‘free text’ comment boxes throughout the survey and the opportunity for respondents to leave contact details if they wished to share their experiences in more detail.

Most who responded to the parents and carers survey took up this opportunity but none of the easy read version for service users did so. One respondent was angry that the survey did not provide;

‘the opportunity to say that transition is disgraceful and totally inadequate on the Isle of Wight for young people. This survey should include people’s views!’

Sadly this respondent despite leaving a name did not leave contact details, and despite efforts to locate them, we were unable to follow up in more detail

We heard from both parents and professionals that a number of families have re-located to the Island as it is perceived as a safer environment. They reported that services are often superior on the mainland, but that the Island provided other benefits. This could mean that the Island has disproportionately higher numbers of children with ASD than other similar areas. We have looked at this in more detail and found the following:

Public Health England: Children with Autism known to schools per 1,000 pupils

Isle of Wight	10.2 per 1,000
Hampshire	4.8 per 1000
England	9.1 per 1000



The Island's statistical neighbours show the following

East Yorkshire 5 per 1000

Cornwall 9.7 per 1000

Whilst the Isles of Scilly shows an extremely high rate at 18.2 per 1000.

We are aware that with such small numbers involved, these figures should be viewed with caution. However, Healthwatch Isle of Wight has contacted our colleagues at Healthwatch Isles of Scilly to find out whether they too find that families with a child with autism migrate to Islands as they are viewed as safe. This could have resource implications into the future.

Although a statutory requirement to begin transition planning from Year 9 (age 14) a number of parents queried the appropriateness of this, as many of their children had no idea of what they would like to do in the future and that at this stage options available to them were not clear. Indeed, we were advised by some professionals that many parents believed that transition did not begin until their child was 18.



Also that in many cases, it was a major task to complete the transition between home and school on a day to day basis and that they had no energy left to consider transition in the long term.

This was echoed by the Easy Read version of the survey with none indicating that professionals had started talking to them about the future at age 14, with 25% being 15/16 years and a further 25% being 17/18 years. 37.5% said that no-one talked to them with the remainder stating that they only had Crisis plans.

Our survey for parents and carers found that; nearly 42% had never had a transition plan and 25% had only ever had crisis plans. None reported having begun plan at Year 9 and the remainder only having plans from year 10 -11 (8.33%) with the rest having had plans at an older age.

The responses to this question and further question hinged on the basis that there was a transition plan and hence elicited lower responses as so few had any plan in place.

We asked parents and carers whether there was a written plan, for 33% or 4 responses with this being yes, 25% no and the remainder not applicable as there was no plan.

For those that had a plan they indicated that the following were included:

Education	33.3%	Benefits and support to claim them	16.6%
Health	66.7%	Housing	16.6%
Transport	33.3%	Travel training	16.7%
Work	33.3%	Relationships	0%
Hobbies, leisure and sport	16.6%	Advocacy and advice	0%
Hopes and aspirations	0%		

Comments included were on the following themes:

Received no further support since their child had left school, with no-one to talk to about the potential for other services. How to deal with medical emergencies and compulsory respite care.

A common thread was having to 'fight' to get any support and being unclear about what 'help' is available

Service users were also asked whether there was a written plan. In the easy read version of the survey, their results were; 25% yes, 62.5% no and the rest not applicable. We also asked what was included in the plan, which elicited the following responses

Benefits and help to claim them	0%
School/college	25%
Where you will live and where you would like to live when you are older	12.5%
What to do if you get ill	0%
What you and others do to keep you healthy	12.5%
How you will travel, on the bus, walk, train or by car	25%
If you need some help to learn how to travel on your own	25%
What you will do for a job	12.5%
Who will help you get a job	0%
Who is important to you, friends, family, carers	25%
Who you need to help you and what they need to do	12.5%
What you like to do in your spare time, things like hobbies and sports or clubs you like to go to	25%
Your hopes of what you would like to do when you are older	25%
No, I can't remember	12.5%
There is no plan	50%

Two Service Users left comments about this question, both reported that plans had not been written down until they were late teens or early 20's with one saying only a crisis had led to a plan being developed.

When comparing the responses from both the Parents and Carers and the Service Users, there are some disparities in responses. For example, hopes and aspirations were not mentioned in the Parents and Carers responses but were by the Service Users, this may have more to do on the focus and recollections about the development of Transition Plans.

Discussions at the workshops and in one to one meetings with parents and carers help provide a fuller picture about transition plans, together with our discussions with professionals in the public and voluntary sector.

The difficulty identified with Transition Plans when begun at school is that they can be limited to education, although social services and other agencies can attend this is up to the parent to organise, without their involvement, plans including all elements can be devised, but without accountable officers for action. One parent identified that following having a series of Social Workers over the course of a year, when nothing changed, a dedicated Social Worker from

the Transition Team has made all the difference. This worker has provided an inspirational lead role in coordinating services, with the transition planning meeting including the Transition Team, Deputy Head of the school, Parent Partnerships (now SENDIASS) and Beaulieu House, as well as the parent and the child. Although the parent recognises this as a comprehensive plan, the child thinks the tool used was not designed for young people with ASD.

A professional described a 'Stop-Start' process to transition for those on Personal Budgets. A young person on placement from a special school, could only stay until Easter, as the school could not afford the one-to-one support required at the placement any longer. This meant the young person would be withdrawn at Easter. Should the young person wish to return after they leave school, then the whole process will have to begin again. People with ASD crave familiarity and routine, so the current method of stop-start does not help the young person, as then the setting has to start all over again with the young person.

This is not a person-centred approach.



We were told by a professional working within the voluntary sector that young people who have not had a Statement or Education Health & Care Plan (EHCP) can fare worse. Whilst they can manage at school, they would need support as a young adult through Adult Services, when they have left school.

Many young people with ASD do not have an EHCP, this can mean them being left at home all day alone when they leave school, when their parents are at work.

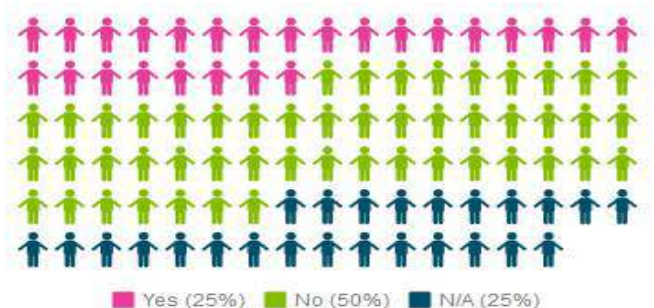
As we did not ask whether children and young people had an EHCP or a Statement in our survey we cannot be sure that this is not the group who identified themselves without a Transition plan, although the guidance is clear that in this event they should have been provided with signposting to appropriate services.

A further complication identified to us, is when Children's and Adult's Services do not work together. An example of this is when parents of children with ASD, have ASD themselves, but the two departments won't work in collaboration. For example, if a child is not being taken to school, it is deemed Children's Services, when it maybe the parent who needs help. This means that neither Adult's nor Children's services take responsibility and leave the family without

effective support. There has been much discussion about how family approaches can be more effective throughout the People Matter IW Service User groups and it is noted that this approach being adopted through the Integrated Early Help Centres.

For the Parents and Carers survey we asked 'was it clear who was responsible for actions included in the plan and when these should be taken' 25% said yes, with 50% saying no and the rest not being applicable. A similar response was elicited by the Easy Read version of the survey.

Was it clear who was responsible for actions included in the plan and when these should be taken?



When asked whether they and their children been encouraged to contribute to the plan; 25% said yes, nearly 42% said no, with the rest not applicable. This was slightly different for the Easy Read version with 37.5% saying that they had been encouraged but this equating to only 3/8 taking part.

Our discussions at the workshops and in one to one meetings with parents provided a fuller picture to this question. Parents we spoke to thought that it would help if a framework of options developed with the family and carers of what was achievable, rather than aspirations were discussed, and that referring back to previous conversations would be helpful in keeping a focus.

We were told one child kept changing their mind with no reflection to what had been discussed before, so it was difficult to progress the plan.

Another told us that her child was very happy in their placement and could stay for another two years, but there was no clarity on whether this would be possible. Whilst parents wanted their children to have a voice in the plan, they were

unhappy that when their child became 18 their views were dismissed. Furthermore, that parents are the expert on their child and that they should have an equal voice in formulating plans.

Professionals had the view that on occasion, parents can sometimes over estimate their children's abilities and play down behaviour that they find hard to cope with, this makes the role of the services harder as they do not get a clear picture of needs. This is because they are frightened to say that they cannot manage certain behaviours as they are afraid that they will 'lose' their children to social services.

However, the same professionals would urge them to make these known so that they can access respite, support and training.

Other Issues

Through our work on this theme we became aware of other issues which do not sit readily under any of our previous headings. They are listed below:

- Parents reported that some services just seemed overwhelmed
- Young people still aged under 25, but who would have been classed as young adults prior to the establishment of the Transitions Team can fall through the gaps in services.
- Young People with High Functioning Aspergers Syndrome can struggle to find appropriate services.
- Communication between Children's and Adult Social Care, together with CAMHS could be improved, and this would aid seamless transition
- Transition is new and evolving, the language accompanying it can be confusing for parents, carers, service users and professionals alike
- The quality of transition should not be dependent on how 'pushy' a parent is.

Transition good practice

The Transitions team is a recently established team to manage young people 18-25 moving from children's to adult services. The aim is to provide a seamless plan for each individual and their families. The team work under the Adult Social Care team.

There are close working relationships with children's teams e.g. Disabled Children's team. A strategic transitions group has been established and is working effectively with senior managers across the Clinical Commissioning Group (CCG), NHS Trust, Adults and Children's Services. A recent workshop brought practitioners together with the aim of developing a transition protocol and increasing understanding about each others duties and responsibilities to the young person e.g. continuing Health Care and Personal Budgets. An operational group is responsible for supporting young people through the very difficult statutory and funding requirements of children and adult services.

Transitions is a high priority for partner organisations and a commissioning agenda is being developed jointly, particularly around increasing the quality of specialist accommodation placements available on the Island e.g. for those with mental health needs, forensic, challenge, with severe autism or severe sensory and physical disabilities.

How this works in practice is given in the example above about the difference made when a member of the Transitions Team led the process and ensured that all actions were taken and that all partners were accountable. The Transitions team is a new team, working within a changing environment, with the impact of the Care Act becoming apparent. However, for those families working with the team the process has become far more effective. One parent noted in particular the need for her child to increase his confidence in order to achieve their aspirations and how this support was provided.

Other actions resulting from the local strategy are also underway and demonstrate good practice, of note is the launch of Autism Ambassadors, the ambassadors are drawn from all sectors and will go some way to ensuring that the needs of people with ASD are met in the community. They will do this through being a positive voice for people with Autism. Raising an awareness of ASD amongst colleagues, friends and family. Identifying and influencing reasonable adjustments that can be made to: work processes and practices, the environment at work or in the community, how people engage and communicate with one another. Build knowledge and sharing of best practice through development of networks.

Forthcoming is the launch of the Autism Alert app for mobile phones, which is already in use in Hampshire. The website describes its uses as follows:

'Should an individual find themselves in a situation with a member of the public, the police or other emergency services, they can present the app in order to communicate their condition. The App also stores personalised information about the individual and their autism, which is aimed to help the emergency services calm and support the individual in the best possible way. This personalised information includes emergency contact details of the individual along with different strategies to help the individual in various emotional states. For example, how to help them if they are sad, angry, anxious or over-excited ('what happens when I get anxious and uncomfortable? I will try and escape by running away and hiding. I may shout and swear at you.' The App has been developed specifically so that it is easy to use. The App has been trialled via a pilot with people with autism and feedback incorporated.

Transition through Continuing Care is another model of good practice. Young people are given a gradual lead in to their placements, just a few hours a week to start with, leading up to a full time placement. Documentation is reported to be comprehensive, so the placement is fully aware about the young person, together with good communication follow up by telephone and email.



The role of the Voluntary Sector is recognised through the Way Forward Programme, both in providing Support Workers and its ASDAN programme. People Matter IW and their Autism Inclusion Matters (AIM) group was also recognised as good practice.

The Isle of Wight College provides much good practice, including the Insights course and the transition provided for young people in order to enable them to access it. Travel training and cookery courses were also mentioned.

In the private sector a taxi service used to transport a young person to college was highlighted (T & J taxis). Driver phoned before collecting child for first time and gave names of all the drivers, also came to see young person the day before the first trip, during the first two weeks, the young person had the opportunity to meet all the drivers.

Practical Support and Carers Assessments

Carers Allowance stopped when child turned 18, but they still live at home and I still provide care'



Our next question asked Parents and Carers if they had been offered practical support or Carers assessments, none indicated that they had, but only 17% indicating that this was because it was not applicable. Only one from the Easy Read version indicated that a Carers assessment had been offered.

Other sources provided further information and explanation. Parents of children/young people who had high functioning Aspergers Syndrome found that Short Breaks did not provide activities that were suitable, in one case a child would not attend as they did not class themselves as 'Disabled'.



The suitability of Carers for this group was also questioned that a different skill set was needed and that this could make children and young people reluctant to engage, leaving the parents with no respite from caring for them.

Others noted that Carers Assessments were not routinely offered as there was a potential cost attached if needs identified and an expectation that Parents would go on being Carers in an unpaid capacity once their child turned 18, even if they had health conditions of their own.

One parent was convinced that she was not offered a Carers Assessment because she was working, therefore had the financial assets to provide care if she needed to.

Of good practice, we noted that Short Breaks was welcomed for being pro-active in involving parents in the offer and being reactive to changing needs. The Way Forward Programme was also recognised as good practice in providing paid for Carers.

Direct Payments and Personal Budgets

'We can't spend the Personal Budget as there is no appropriate support for xxx, now Social Services want it back'

Our survey found that 25% of Parents/Carers indicated that their child received a Personal Budget with a further 25% indicating that their child had Direct Payments. Service Users survey found that 37.5% had a Personal Budget, 12.5% had a Direct Payment and 50% received neither.

From our discussions with parents/carers and professionals within the voluntary and to a certain extent the statutory sector, we understand that there is a lot of confusion is attached to the purpose of Personal Budgets. It is understood that there is little use of Direct Payments locally, hence the responses given to a survey regarding Direct Payments are questionable.

The use of Personal Budgets is also often discussed both at the People Matter Isle of Wight Service User groups across the board and at the popular Parent's Voice Coffee mornings. There is much frustration expressed about the lack of clarity in which they are calculated and the rules used. It seems that no-one in receipt of a Personal Budget understands how calculations are made. Further that there are disparities in the amount of contributions clients have to make to their Personal Budget's an

example we were given was, that those living independently seem to have to pay more than those living with their family. To the extent that for one client of a voluntary organisation it has been suggested that they no longer receive a Personal Budget, as their contribution to it will be higher than what they receive from it.

The Isle of Wight Local Offer describes a Personal Budget as an amount of money or resources available in order to deliver the outcomes set out in a plan. The total Personal Budget should be made clear to parent and carers so they can be involved in all decision making in order to choose the right provision to best meet the outcomes identified in the child or young person's care plan. For any of the three services, social care, health and education, to deliver a personal budget the eligibility criteria for each service will need to be agreed.

Personal budgets can be made up in the differing ways.

An organisational arrangement

No money changes hands. Parents/Carers find out how much money is available and with support identify the different ways to spend that money meeting the outcomes of the child's care plan. The services are then arranged on the family's behalf by the local authority or health service.

Direct payment

Parents/Carers are given the money to buy and manage the services themselves to meet the outcomes identified in the child's care plan.

A combination of the above.

As part of the funding identified through the assessment process, some Parents/Carers may want to use a reasonable amount of their available resources to help meet the outcomes identified in their child's care plan.

Healthwatch received a plethora of comments and views about Personal Budgets. Parents/Carers found that recent changes made them too prescriptive and 'clever' wording had to be used to ensure a child/young person got all the services that they needed. There was confusion on whether a Personal Budget could be used for travel to and from activities.

Also that Care Managers could give different parameters on what a Personal Budget could be used for and that they were also reluctant to name services for fear of it being construed as a recommendation, leaving parents unsure what services that they could buy. Professionals raised queries about the monitoring and quality of providers, currently there are no inspections of services.

We raised this issue in regard to the Short Breaks programme, and were advised that Quality Assurance procedures were in place, these included, Parents Voice representatives as part of funding panels, DBS checks completed, Health and Safety policies together with Risk Assessments and Safeguarding procedures.

They have also instigated the 'Young Inspectors' programme where peers review services. Data monitoring is also gathered on a monitoring basis, Healthwatch would commend a similar approach to all service providers, especially where services are purchased through a Personal Budget.

Parents Voice Isle of Wight have been active in providing parental representation on the development of Personal Budgets, together with the Local Offer and Education Health and Care Plans. They are aware that improved reporting and feedback by their representatives would increase understanding amongst other parents and are working to achieve this.

Professionals also noted the difference in transition arrangements for young people were dependent on whether they were in receipt of Personal Budgets or Continuing Care. For the former it was noted that the process seemed slow and disorganised and in comparison the latter was described as 'fabulous'



Health care, including Mental Health

Although our focus was on issues and good practice around Transition, parents and carers welcomed the opportunity to raise concerns about the health care their child had received and its appropriateness for children and young people with ASD.

 A child too frightened to attend Children's Disability Dentist was removed from their register for non-attendance. 

 A young person on reaching adulthood and hence no longer entitled to Children's Disability Dentist now cannot find another NHS dentist experienced with treating people with ASD to register with. 



 Speech and Language Services- several parents reported that it took over a year to access the service, parent believes this was due to staffing issues. 

 For children with ASD who also are deaf, hearing aids can provide a sensory overload, it was queried whether audiology staff are trained to deal with this, as it can mean that children will refuse to wear aids. 



 Many parents noted that although there is an Adult Learning Disability Nurse, who is also experienced in supporting people with ASD at St Mary's, there is no similar provision for children. 

 The appropriateness of an adult ward for a young person aged 18 with ASD was queried. 



 A child who became violent when depressed, with the parent having no idea where they could seek help. 

 A child who was due for day surgery had the surgery cancelled, so had to attend a further pre-assessment. The child was very reluctant to attend, because as far as they were concerned this was just duplication and served no purpose. 

 The appropriateness of Saturday morning club for children with ASD was questioned, a more personalised approach would be preferred. 

 Parent reported that the Paediatrician has been superb, but worries what will happen when her child turns 18 as he will lose this important source of support. Paediatrician carried out a final blood test before signing the child off. Child suffers from eating and sleeping problems and Paediatrician will prescribe Melatonin. However GP will not prescribe it as they are unsure if it is licensed. NHS Choices advises that Melatonin should only be prescribed for short periods and is unsuitable for the under 55's. If the family is unable to get it from their GP they will buy it from the internet, with the associated inherent risks. Parent is aware of other parents who have registered their children with GP's in Southampton to ensure that they can get Melatonin. 

 Example given of child with Downs Syndrome and ASD, the needs addressed are those of Downs Syndrome not ASD. 

 Parent reported a very poor experience of Mental Health services for her young adult child. Parent felt that Chantry House tried to dismiss her concerns and reportedly said 'xx doesn't want help, therefore we cannot help'. On one occasion parent rang in Chantry House in desperation and was told 'we'll put some leaflets in the post'. When the leaflets arrived they were for voluntary work. The parent describes this whole episode as a terrible, horrendous experience. The Parent was concerned that her child was suicidal and engaged legal support and complained. After this, they received good support via Chantry House. 

Benefits, JCP and access to employment, including access to advice services and financial literacy

An area outside of Healthwatch's remit was that of benefits, Job Centre Plus (JCP), access to advice services and financial literacy, we include these issues as they relate to transition and should become part of the service delivery, as they are crucial to the successful transition to adulthood.

- Child in early 20's quite capable of working, but doesn't, as they need supported employment, but this doesn't seem to be an option. JCP seem quite happy to keep him on benefits.
- Child has numerical dyslexia, so despite having a degree, can't even get a job in a shop, parent can find no-one to help overcome this.
- DWP still consider parents responsible after the age of 18 and write to them.
- Completing DLA and PIP claims are difficult for some parents especially those who have a Learning Disability themselves or who have never had cause to claim benefits in the past and they report long waiting lists at CAB to help them do this.
- There were reports of some young people being in receipt of JSA as there was no-one to support them to claim ESA or DLA although this was the most appropriate benefit for their needs.
- When a young person got their P60, they thought it was extra money and went out on a spending spree.
- A young person who currently does some work on a self-employed basis, doesn't complete a tax return. The parent does not have the skills to help them and worries about the young person's liability for unpaid taxes.
- Parent reported that a letter from the council for her child about registering to vote had arrived stating that there is a £60 fine if they failed to register. The parent rang the council and explained that the child had ASD and was told not to worry. A further letter was then received from the council stating that failure to register to vote would lead to an increased fine. This caused a great deal of anxiety as the child does not wish to deal with the issue or, indeed, vote.

We were told that financial literacy education would help overcome some of these issues. Parents were also worried that their children, as young adults could apply for credit cards and go on spending sprees without the means to pay back the debt accrued. We understand that benefits and financial literacy are now discussed with young people as part of transition, but parents and carers feel that there should be more emphasis and support in this area, particularly for those young people who are now in their late teens and early twenties.

Housing and Independent Living

Parents and Carers were confused about what constituted independent living as ASD is a spectrum. They were unsure how providers would ensure the right level of support was in place. They also identified a need to plan and anticipate housing needs within the ASD community. In the main they did not know what options there could be.

When moves to independent living took place they reported that quite often it can be rushed and last minute with no chance of rehearsal or transition. For one parent there was a real worry, that as their child could become extremely anxious and that this could manifest as aggressive behaviour if a visit was not organised properly.

Parents and Carers also identified a need for young people to learn how to deal with emergencies. For example, one young person stood

and swore when the toaster caught fire at home, but had no idea what to do. When a parent collapsed, the young person stepped over them, and made no effort to help or call the emergency services. On this issue, they also thought that young people should be taught to use a telephone, as this was mentioned as a common issue, with young people nodding and shaking their head whilst on the phone rather than speaking.

Some of issues raised above, particularly around dealing with emergencies, are what parents of all children need their children to learn. The Parents Voice Coffee Mornings provide a useful meeting point for parents to discuss and learn from each other on how best to tackle these challenges. Other good practice we heard about was the Way Forward ASDAN programme for independent living.



Education

Another area outside of the Healthwatch remit of health and social care is that of education, nonetheless, Parents and Carers were keen to talk to us about their experiences. The issues raised here could provide useful learning points for professionals working in education.

Words frequently used by parents were 'fight' and 'micro-manage' to get assessments and the right support for their child. Diagnosis is seen as a 'passport' to the support. It is worth noting that not all children with ASD would have had a Statement of Special Educational Needs (SEN) or Education Health and Care Plan (EHCP), but they will still have the same needs for transition support. Some children with ASD thrive in the structured education environment, but would need appropriate support to flourish in adult life. Parents queried the appropriateness of schools leading transition as when a child leaves school their responsibility ends.

Other children cannot cope with the standard school environment, one parent reported home schooling her child for a number of years as there were no appropriate placements, the child is now placed in a public school, which the council fund, however, the parent has to

pay for and supply the equipment required by her child to integrate fully into the school environment.

Parents generally welcomed EHCP's as providing a means to more holistic support for their child, as they extend to age 25, parents aimed to keep their child in education until then, acknowledging that this did not solve the transition 'issue' rather just delayed it. Professionals working in the area recognised that a child needed to be supported in transition throughout their school life, from primary to secondary, then further education and adulthood.

Parents noted particular good practice at the IW College and their Insights course. They praised good transition by the staff team and SENCO's over the summer holidays prior to commencing the course, and fully supported work placements. They found that there was good personalised planning and opportunities to meet with older students and learn from their experiences was welcomed.

Other good practice mentioned was the ASDAN course run by the Way Forward programme as mentioned previously and Bodster Equine Therapy.



Transport and travel training

Parents most positive experience of transition was travel training provided by IW College, it was regarded to be very thorough and effective leading to fully independent travel by bus.

Although one parent noted that because they lived in a rural area, their child was never likely to achieve independent travel as the area was poorly served by public transport.

Generally, parents struggle to find out where to access services and what is available, for example, travel training seemed to happen by chance. Parents said that it should be planned in prior to work experience, otherwise children won't be able to get there.



Safeguarding

During the course of this research we became aware of a potential safeguarding issue relating to the parenting of some children with ASD. Whilst to protect confidentiality we cannot be specific. We have raised this issue to be considered by the Local Safeguarding Children's Board (LSCB) and the Early Help team at the IWC.

We understand that the LSCB is to undertake a 'task and finish' group to further examine the issues facing all children with disabilities. This is an issue recently raised by the NSPCC in their report with The University of Edinburgh 'Deaf and Disabled Children talking about Child Protection.

Conclusions

ASD is a relatively recently recognised diagnosis, people with a diagnosis all have different needs as it is a 'spectrum'. For many older adults a diagnosis would never have been made and they would have just had to develop coping mechanisms to function on a day to day basis. In comparison, children and young people today have the prospect of having fulfilling lives and achieving their aspirations with the right support and preparation.

However, statutory services have had to undergo some profound changes in response to changing legislation in health, care and education, as well as working with ever decreasing budgets, delivering more for less. Locally, it is acknowledged that there is shortage of social workers, with recruitment proving difficult, which can also impact on the support provided. Social workers do not always have the time to build relationships with their clients. They can fail to recognise their parents as 'experts' on their child, or even post 18 exclude them from the transition plan process. Other government agencies, notably, the Department for Work and pensions, still regard parents as responsible, this is both perplexing and disempowering for them.

Confusion on what is the right terminology, use of language, access to advice and rights information, advocacy together with general communication issues can leave parents and carers

disillusioned with services, or feel that they have to 'fight' every step of the way to get the services that their loved ones need. Many of these issues together with further clarity around Personal Budgets are now being addressed through the provision of the Local Offer, this is a real resource and is being further developed. Awareness raising, which is already on-going about its existence and purpose, is key to resolving many of the above issues.

For those young people who did not have an EHCP or a statement the Local Offer also provides the effective signposting required to meet their needs. During the course of this work we were advised that young people, or their parents/carers can still ask for transition support from social care, where there are needs.

The IWC have been pro-active in engaging with parents in the Local Offer, Personal Budgets, and EHCP, together with Short Breaks through Parents Voice Isle of Wight. However, Parent's Voice and the IWC should take further steps to engage with the harder to reach families and ensure that their views are also represented. There is always a risk of representation from service users becoming a single voice rather than a collective one.



This is an issue which both parties are aware of, with strategies to achieve better representation underway. As part of this, it is important to communicate the limitations of any service, as those who are not fully engaged can feel further excluded if they do not understand the context in which an offer is being made.

The establishment of a dedicated Transition Team is a very positive step forward, the difference in the experiences between those who are undergoing transition now to in previous years is markedly better. That is not to say that is not without its issues. We understand that there is great demand now and into the future of this service. The issue previously mentioned and a backlog of reviews can explain some of the anomalies noted in the parameters in Personal Budgets for different individuals. The implications of the Care Act particularly in terms of case law is yet to be felt.

A revisit to this topic in 18 months may provide a better insight into the improvements seen by service users, their parents and carers.

The new Integrated Early Help Centres will also have a role in transition and their services will also be fully operational by then. Although there is an inconsistency in that the Integrated Early Help Centres for children and young people do not extend to age 25 where a young person has additional needs, this is at a variance to other services for children and young people with additional needs.

For young people who began their transition to adulthood prior to the new focus on transition; it is important that they do not become 'lost'. One parent told us her child aged 23 received no support or services and was just left at home, with no job or activities, and becoming at risk of mental health issues due to their isolation.



Recommendations

Healthwatch Isle of Wight makes the following recommendations. Statutory services are required to respond to them within 20 working days.

Isle of Wight Council:

1. Continue to provide and develop the Transitions Team service and ensure their involvement from the start of transition, recognising that schools may not have a role post 16, particularly where there is an entry requirement for post 16 education. Ensure that other relevant agencies are involved and accountable for their actions. Provide further clarity and detail on Personal Budgets and Direct Payments, particularly on calculations and parameters and communicate this effectively.
2. Advise on and provide Carers Assessments as a standard procedure to all Parents/Carers who are supporting a child/young person with ASD. The resulting needs may cause increased demand on Carers Isle of Wight, so there should be some anticipation of increased resource for them.
3. Ensure Parents and Carers know where they can access advocacy and how it can help them. As above this may increase demand and there should be increased resources for these services.
4. Include an increased focus on financial literacy, access to work and benefits as part of transition planning.
5. Ensure that older young adults receive the same quality of transition planning as those just entering the process, auditing where young people appear to have lost contact with any service.
6. Extend the Integrated Early Help Centre 'offer' to include young people up to the age of 25 where they have additional needs
7. Review the transition planning tool (EHCP Review) to ensure that it is suitable for young people with ASD and providing a framework of options, but retaining space for aspirations, this recommendation is backed up by the findings of a 'Young Inspectors' report, that wording should be adapted to fit different assets and needs
8. Consider developing whole family based approaches to ensure issues are not dealt with in silos, this will fall under the My Life A Full Life umbrella and will happen in due course.

Isle of Wight Council Recommendations (Continued):

9. Review care and Short Break services to ensure their suitability for children and young people with high functioning Aspergers syndrome. Where services are already available for these groups they should be communicated effectively to these specific groups. A review function by children, young people and their parents/carers on the Short Breaks website would assist this. A review function is already available on the Local Offer website. This good practice could be replicated.
10. Ensure that those harder to reach families and that those on the periphery have a voice when developing services. Parents Voice, People Matter IW and the IWC should take further steps to engage with the families mentioned above. There is always a risk that service user representation becomes a single voice rather than a collective one. As previously stated this is an issue of which all parties are aware, with renewed vigour being used in strategies to achieve better representation. As part of this, it is important that the limitations of any service or service type is communicated, as those who are not fully engaged or are on the periphery feel further excluded if they do not understand the context in which an offer is being made.
11. Regularly assess the housing needs of those with ASD to ensure that there is sufficient suitable housing provision and anticipation and planning for needs in the future
12. As the IWC moves to become a commissioning authority that consideration is given to current voluntary and private sector providers of services to deliver transition in the future.

Health: Including NHS Trust, Dentists, GPs and the Clinical Commissioning Group Recommendations:

1. There is a new guide for GP's about reasonable adjustments, we would recommend this to all health professionals, together with more focussed Autism awareness training where appropriate. This should include staff in the audiology department about sensory overload for deaf children with ASD
<http://www.rcgp.org.uk/clinical-and-research/clinical-resources/-/media/Files/CIRC/Autism/RCGP-Making-the-most-of-a-visit-to-your-GP-Jan-15.ashx>
2. That a post of Children's Learning Disability Nurse be established to provide a service equivalent to that provided by the Adult Learning Disability Nurse, of which we heard much praise. Adoption of the Autism Ambassadors programme within the hospital would also be recommended.
3. That a review of the Saturday morning club be conducted to assess its accessibility for children and young people with ASD
4. Consideration of appropriateness of admitting young people 18+ with ASD on adult wards.
5. Clarification required on the parameters for the prescribing of Melatonin and availability of sleep training

Review

Healthwatch Isle of Wight will review the findings of this report together with progress on its recommendations during the Winter 2016/17

References

NHS Choices - www.nhs.uk

Autism Strategy 2015 - www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance

Special educational needs (SEN) code of practice - www.gov.uk/government/uploads/system/uploads/attachment_data/file/273877/specialeducational_needs_code_of_practice.pdf

Autism Act 2009 - www.legislation.gov.uk/ukpga/2009/15/contents

Adult Autism Strategy 2010 - www.gov.uk/government/news/fulfilling-and-rewarding-lives-the-strategy-for-adults-with-autism-in-england

Adult Autism Strategy 2014 - www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy

www.Autismspeaks.org

Community Engagement in Initiatives addressing the Wider Social determinants of Health - Popay et al 2006

NICE Public Health Guidance PH9 - Community Engagement 2008 - *currently being updated* www.nice.org.uk/guidance/ph9

Isle of Wight Voluntary Sector Forum - www.communityactionisleofwight.org.uk/what-we-do/support-for-voluntary-groups-charities/voluntary-sector-forum

Think Autism - Update of the Adult Strategy - www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy

National Autistic Society - www.autism.org.uk/

The Care Act - Statutory Guidance Care and Support - www.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf

United Nations Rights of the Child - www.unicef.org

Isle of Wight Local Offer - www.iwight.com/localoffer

Isle of Wight Joint Strategy for Children, Young people and Adults with Autism 2014-19 - www.iwight.com/azservices/documents/2703-Autism-consultation-strategy.pdf

Public Health England Children with Autism known to schools per 1,000 pupils

<http://fingertips.phe.org.uk/profile/learning-disabilities/data#gid/1938132702/pat/6/ati/102/page/3/par/E12000008/are/E06000046/iid/91436/age/217/sex/4>

Isle of Wight Council Transitions Team - www.iwight.com/Residents/Care-and-Support/Adults-Services/Adult-Social-Care-Preparation-for-Adulthood/Overview7

The Way Forward ASDAN programme - www.wayforwardprogramme.co.uk/ASDAN.html

People Matter Isle of Wight - Autism Inclusion Matters (AIM) - www.peoplematteriw.org/involvement-groups/4576855921

Isle of Wight College Insights Course - www.iwcollege.ac.uk/courses/insights/insights-progression/

Autism Hampshire - Autism Alert App

<http://www.autismhampshire.org.uk/support/outreach/autism-alert-app.html>

Isle of Wight Local Offer - Personal Budgets - www.iwight.com/localoffer

NHS Choices - Melatonin - www.nhs.uk/medicine-guides/pages/MedicineOverview.aspx?condition=Insomnia&medicine=melatonin&preparationMelatonin%202mg%20modified-release%20tablets

Bodster Equine Therapy - www.eaqbodster.co.uk/Home.html

www.nspcc.org.uk/globalassets/documents/research-reports/deaf-disabled-children-talking-about-child-protection.pdf

Making the most out of a visit to your GP - www.rcgp.org.uk/clinical-and-research/clinical-resources/-/media/Files/CIRC/Autism/RCGP-Making-the-most-of-a-visit-to-your-GP-Jan-15.ashx

Annex 1

Questionnaires

Survey for Parents and Carers

1. At what age did plans for transition begin
 - Age 14 (Year 9)
 - Age 15-16 (Year 10-11)
 - Age 17 -18
 - Older
2. Was a written plan drawn up?
 - Yes
 - No
3. If yes was it clear who was responsible for actions and when these should be taken?
 - Yes
 - No
4. Did the Transition plan include the following - indicate all that apply
 - Education
 - Health
 - Housing
 - Transport
 - Travel training
 - Work
 - Relationships
 - Hobbies, sport and leisure activities
 - Advocacy and advice
 - Hopes and aspirations
5. Were you encouraged to contribute to the plan
 - Yes
 - No
6. Were Carers or parents offered practical help/carers assessment?
 - Yes
 - No
7. Do you receive?
 - Direct Payments
 - A Personal Budget
 - Neither
8. Would you be willing to share your experiences in more depth with Healthwatch Isle of Wight?
 - Yes - please let us know your name and preferred contact details
Name:
Phone:
Email:
 - No

As a child you may have had support from social services, mental health and others, these are often called Children's Services.

As you grow up you move onto services that are called Adult Services.

The time as you move between these services is called 'transition'

We would like you to answer questions about what happens in the time that you are moving from Childrens Services to Adult Services.

This is from about the age of 14 but you may be older.

Thank you for completing these questions.

Healthwatch Isle of Wight will use your answers to try and make life better for you.

1. Can you remember how old you were when people started talking about moving you from Children's Services to Adult Services?
Please put a ✓ tick next to just 1 answer

Were you

- 14? This is Year 9 at school
- 15 or 16? This is Year 10 or 11 at school
- 17 or 18
- Older
- They didn't talk to me
- I don't remember

2. Did someone write down a plan for you?
Please put a ✓ tick next to just 1 answer

- Yes
- No
- I didn't have a plan

3. Can you remember if the plan has these things in it?
Please put a ✓ tick next to all the things that are in the plan

- School, college
- Where you will live and where you would like to live when you are older
- What to do if you get ill
- What you and others can do to keep you healthy
- How you will travel, on the bus, walk, train or by car?
- If you need some help to learn how to travel on your own?
- What you will do for a job?
- Who will help you get a job?
- Who is important to you? Friends and family and carers
- Who you need to help you?
- What you like to do in your spare time? Things like hobbies and sport or clubs you like to go to

- Your hopes of what you would like to do when you are older?
- No I can't remember
- There is no plan
- Is there anything else in your plan. Please write down what else is in your plan

.....

4. Do you know who needs to make each thing in your plan happen?
 Please put a ✓ tick next to just 1 answer

- Yes
- No
- There is no plan

5. Do you know when things are meant to happen?
 Please put a ✓ tick next to just 1 answer

- Yes
- No
- There is no plan

6. Did the people who wrote the plan ask for your ideas to help write it?
 Please put a ✓ tick next to just 1 answer

- Yes
- No
- There is no plan

7. Do you know if your parents or carers were asked if they wanted help to look after you
 Please put a ✓ tick next to just 1 answer

- No I don't know
- Yes they were
- No they were not

8. Do you get money called any of the following?
Please put a ✓ tick next to just 1 answer

- A personal budget
- Direct payment
- No I don't get either
- I don't know

9. Would you like to tell us more about the Children's or Adult services

- YES PLEASE –

Tell us your name and the best way we can contact you, this can be by telephone, by email or by writing you a letter

Name

The best way to contact me is by telephoning me on this number

The best way to contact me is by sending me an email at

.....

The best way to contact me is to write me a letter (this is where I live)

House number or name

Street

Town

Post code

- NO THANK YOU - I don't want to tell you any more

Thank You from Healthwatch Isle of Wight



Are you an adult who has Autism, Aspergers or ASD?

We'd like to hear your experiences on the transition from Children's to Adult Services and use your feedback to make the services better for the future.

Your view could help make transitions better in the future!

We will be holding two workshops on the following dates, both of which will have tea/coffee and biscuits for you.

Winchester House—18th March 2015, 6pm—8pm

OR

Downside—25th March 2015, 10am—12pm

No need to book, just turn up! Either by yourself or a parent/carer.

If you can't attend but would like to chat with us, call us on 01983 608608 or fill in a survey online! <https://www.surveymonkey.com/s/7Q5QTMT>

Appendix 3

Background papers

<http://preparingforadulthood.org.uk/what-we-do/joint-commissioning/pfa-guide-to-joint-commissioning-resources>

National Autistic Society – Autism & Transition

Green Light Toolkit 2013

National Autistic Society-Don't write Me Off – make the system fair for people with autism

Research Findings from studies on Transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) (*Internal Healthwatch Isle of Wight research*)

The Isle of Wight studies: “Into the Future – Report on Community Mental Health Services for Adults” (LINK 2012) and “Bringing it Together – Looking at Mental Health Support for local Children and Young People” (Healthwatch, 2013) identify a number of issues that arise for young people who are recipients of mental health services.

These issues are reflected in other research studies across England. The point of transition from CAMHS to AMHS is identified as a particular area of difficulty for service users.

Complex Conditions

The Social Care Institute for Excellence suggest that the process of transition between services is particularly difficult where service users have complex conditions. Those with learning difficulties, Autistic spectrum disorder and ADHD often expressed the view that they did not receive appropriate help from adult services and were therefore likely to disengage from the service.

They also found that there were inadequate services for particularly vulnerable children and young people such as asylum seekers and travelers.

The Care Quality Commission (2000) found that those who disengaged with CAMHS or AMHS were more at risk of becoming; homeless, abusing alcohol and drugs and to also disengage from education or training.

Communication

The Health Select Committee (2000) identified that there was a failure of services working together.

The Report for the National Institute for Health Research Service Delivery and Organisation Programme (Jan 2010 Lead author Prof. Swaran P. Singh, University of Warwick.) found that across mental health services across London and the W. Midlands that conflicts between professionals in cross boundary work resulted in problems with service transition for young people.

Young service users and some CAMHS professionals identified a different ethos in adult mental health care was a source of difficulty with some stating that adult services adhered to strictly to a medical model of mental health difficulties.

Service reported feeling depersonalized in adult mental health services and some said they had no key named worker.

Some service users reported being cut off from CAMHS and moving into adult care with little or no planning. They found that they often had to repeat their stories on a variety of occasions due to a lack of continuity of care. At this stage service users were more likely to disengage with Adult Mental Health Services

The Warwick study found that in one area in the W. Midlands only 4 out of 90 service recipients making the transition had any partial joint working or transitional planning and that examples of good practice were extremely rare.

Many professional were dissatisfied with the transition process and cited that high caseloads made it difficult to work effectively on the transition process and maintain continuity of care.

Barriers to Transition from CAMHS to Adult Mental Health Services

At the point of transition some service users had their services discontinued. This was because they did not meet the criteria for adult services which mainly focus on enduring and psychotic conditions.

Those with severe and enduring mental health problems who had been admitted to hospital and on long term medication were most likely to be accepted by adult mental health services.

Where service users were not accepted by Adult Mental Health Services they were often cut off from all support services. This was viewed as a problem by service users and their parents and carers.

Where recipients were accepted by Adult Services the Warwick Studies indicated that families and carers felt left out of the process. In CAMHS they are very often involved in treatment but this tends to diminish in adult services which was often more individually focused.

A differing ethos between Child adolescence and adult services arose again for some service users who thought that the aims of practitioners were different to their own and those of the children and adolescent services.

In- patient facilities for Children and Young People

The Social Care Institute of Excellence state that too many children and young people are placed in psychiatric units away from their homes and that this leads to a lack of continuity of care with a known and trusted person.

The Health Select Committee (2000) said that young people were travelling long distances to receive treatment making it very difficult for family and friends to visit.

The Warwick Study indicated that many young people were transferred to Adult Services when they were admitted to hospital

Recommendations for improving services

SCIE make a number of recommendations for improving mental health services for young people:

- The young person's whole life should be taken into account rather than solely a medical approach
- Planning for transition of care should start at least 6 months before the change of service is made.
- There should be collaborative work between, health and social care and voluntary services
- There should be a named key worker for all service recipients and peer support services
- Information should be given to service users both verbally and in writing
- Services should be welcoming and approachable
- Continuity of staff for service users so that service users do not have to keep retelling their stories
- Services should be flexible so that they can be stepped up or down with changing needs.
- There should be access to services for vulnerable groups such as asylum seekers and travelers.

The Health Select Committee (2000) stated:

- That no young person should be admitted to adult psychiatric care units.
- That children and young people should be placed in age-appropriate facilities.

The Warwick publications recommend:

- Joint working across the Mental Health Services including professionals from CAMHS and AMHS attending joint case conferences and passing on records and notes to a key worker.
- Designated transition workers to guide through the whole process of transition between services
- Information packs given to service users making the transition
- Transition log books to be worked through with key worker containing contact numbers.
- Some service recipient and parent choice in timing of transition
- Move to a more social model and away from a medical model of engagement and practice.
- More psychological therapies to be made available to service recipients
- Available contact for those not continuing into AMHS.

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