The Transition and onwards….

Teenage years can be challenging. Preparing for adulthood where the transition into adult services is needed is even more challenging; for your son and also for the family. The emotional, practical and decision making issues involved are demanding and all happening simultaneously. To have to really think hard about the future - make applications for new benefits, go through assessment processes, make new education plans - can be tough.

I am going to give an overview of the process as a whole which I hope will be helpful. I would also like us to have some open discussion and exchange some of your knowledge and experience as well.

The 3 stages we will look at are:

1. The pre-transition period in which we plan for moving from childrens’ to adult support services
2. The actual transition between those services
3. Ongoing into xxyy adulthood

I will just mention that when I refer to social worker or care worker, they are loose terms to embrace whatever support you may have in that regard.

In addition, I have prepared a pack for each family who may like to take one at the end of this session which will include an appendix. The appendix gives more detail and useful references on the various issues we will look at this afternoon.

Pre-transition:



Moving from the child to adult services has been described as diving from the pond into the sea. Hence, timely preparation for it needs to begin 3 or 4 years in advance. It is important to take time to recognise what your sons needs may be, what you and your family needs may be and an understanding of what the system offers.

Here are steps in that process:

* Once your son is 12/13 years of age talk to him about his aspirations. He needs to feel that he will be an equal partner in any decision making and that his wishes are regarded seriously.
* Discuss with him and his siblings about his aspirations. Unrealistic aspirations can often be handled better by siblings or other family members rather than parents! They can often redress the balance more effectively.
* Based on this previous discussion, talk with his GP and care/social worker your son’s capabilities and mental, physical and social needs. Your son should be present and be free to give his input. It is not always easy to arrange a meeting of everyone together. Sometimes you have to exert some authority and insist on it happening but they need to be fully aware of what support you anticipate needing.
* Discuss with your son’s GP and care/social worker the transition process from child to adult services. Get to know the system for yourself. You may find yourself in the position of informing them but you need them on board as they are the people who can then activate processes and make referrals.
* Compose a draft care plan along with your son, GP and care/social worker of all aspects of support that will be needed :
* establish regularity of health checks. Some of these may already be in action.
* name recommended medical professionals (or at least the relevant departments) for his physical and mental care
* availability of further education; appropriate local college courses or training for work/employment
* availability of benefits/ grants. (See Appendix/Benefits)
* Independent living. (see Appendix/Housing)
* money management (See Appendix/Money management)
* Establish your son’s agreement on advocacy, power of attorney
* Review annually, with your son present, until time comes to activate.

There will be an opportunity later to revisit and discuss these points more fully for anyone who would like to.

Ensure that your son is comfortable throughout these processes and just hope that out of it all he will eventually be like Winston Churchill and say ‘when I was 16 I thought my parents knew nothing. By the time I was 21, I was impressed at how much they had learnt in 5 years.’

Transition:

I assume that at present you will be in one of 3 situations:

* as a parent, already attached to the children’s services system with transition approaching as your son gets older.
* as a parent, not attached to children’s services but looking at support for your son in the adult services.
* you are advocating as a carer.

If you as the parent, are not the advocate, the person who takes that role must know your son well and be involved throughout the transition preparation process.

As many of us know, the bureaucracy of adult services can make it complex and bewildering. As advocates, we are the driving force by which to gain the best support we can. Once we reach this stage of transition we need FIRM FOCUS and energy to execute what we have previously established and planned for our sons’ needs.

So when the time comes the following need to be firmly in place:

* a permanent Care Plan which is an entitlement for ongoing medical, mental and social support. It should set out:
* your son’s medical needs
* daily living requirements
* management of money
* management of time
* support required in college/work
* his aspirations for the future

The advocate needs to oversee that regular appointments are made by the professionals – and kept by your son.

* applying for relevant financial support (see Appendix/Benefits). This will require some time consuming form filling and possibly interviews. At any interview arrange beforehand that it will be recorded. You will probably have to provide the recording equipment for two simultaneous recordings – one for you and one for the authorities. This can be used as evidence if the outcome of an interview is clearly misrepresented.
* establishing good relations with new care/social worker. Ensure regular reviews.
* establishing good relations with tutors (further education) or employer so that they know you are approachable in the event of a problem.
* ensuring support provision for commencing further education/college/work. This can be arranged through your care/social worker.
* raise the issue of any ‘gap analysis’ where a particular support has been provided in children’s services which is no longer apparent in adult services but is still considered necessary. It is very likely that it can still be provided though through a different channel.
* the right professional support – either rereferral to previous practitioners or establishing better alternatives.
* ancillary support eg: travel passes (see Appendix/bus passes, blue badge etc:))

If you have never been connected to children’s services but are considering the need for support from the adult system, you will need to apply for a form from your local authority adult social services department. Complete the form by answering the questions with the worst possible scenario. As parents we tend to look at the best outcome – but not on this occasion! Take every opportunity to add an adverse unfavourable comment to a ‘yes’ or ‘no’ answer.

For example, the question may be ‘can your son wash himself?’

The answer could be ‘Yes but he has to be reminded daily to do that’.

The Care Act of 2014 entitles you to an assessment process at any stage. If your son has passed the ‘16’ transition age you can still set up a care plan and go through the process as already set out. You may just want to make an application for your son but a holistic assessment can be twofold:

* to assess your needs as a carer
* to assess your son’s needs

And on into adulthood!

Some key words here:

Communication – to maintain good relations is vital.



* with your son – it can take time and sometimes, patience. If he is mentally not in a good place, avoid confrontation. He can’t handle it logically. Wait for a better, quieter and calmer moment.
* between all professionals involved. Ensure (whether you accompany your son to the appointment or not) that each practitioner has a copy of Dr Tartaglia’s paper on xxyy. Also inform each practitioner of any mental or physical health problems that may have arisen since the last appointment. Keep them all up to date at each step of the way.
* between family members. Family members can contribute valuable ideas to enhance your son’s quality of life. Discuss the development of positive aspects as well as your concerns, your son’s concerns and any specific problems.
* with friends. Help them to understand 48xxyy. We have done this through our annual barbecue in raising money for Unique. We put a little write up about Stephen on the invitation. We also talk openly about the situation.

Security - vulnerability needs routines in order to protect



- a structured day. Occupation is paramount. It is not always easy to find and often has to be

arranged by a parent. Examples of National Trust voluntary work, Ground Works, Blythstar…..

- staged support in new situations (care worker can accompany in a new work environment). We can

all find a new work situation daunting but how much more so for someone who finds social

interaction difficult. Staged support can make a huge difference until confidence is gained.

- employers/course tutors aware of 48xxyy behavioural implications. Speak to them personally

before the starting date and provide them with Dr Tartaglia’s xxyy paper.

- wearing a name disc for xxyy. Unique provides these. It is useful in the case of hospitalisation or for

any confrontation with the police.

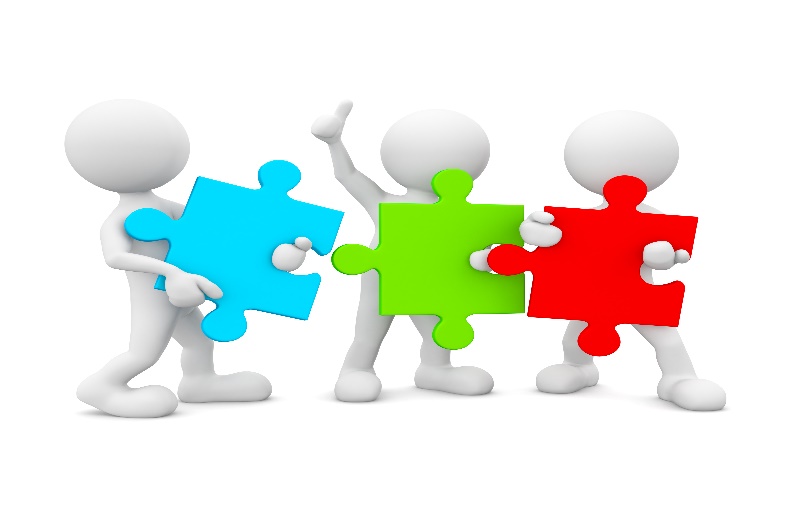
- an operative mobile phone set with core telephone numbers for easy access.

Building Independence – this is the paradox!



* finding a housing resolution. Your son may naturally want his independence particularly if he has siblings who he sees as ‘moving on.’ (See Appendix Housing options)
* giving responsibility for making arrangements where applicable.
* Ensuring that he takes responsibility for tasks in the home
* organising/overseeing local travel on public transport.
* organising/overseeing activities/holidays

Co-ordination – between the services



* ensuring activation of the care plan dates eg: annual/six monthly routine checks
* raising awareness with all medics of any untoward medical or mental problem
* raising awareness to medics/college staff/employers of any other relevant, significant changes

Advocacy



We need a strong voice. No one else will speak for our sons but do that effectively there are a few things we need to do:

Be aware of the Mental Health Act

Keep abreast of the ongoing government proposals for disability rights.

Be involved in local groups that support disability eg: LDBP

Inform your local MP when things go wrong with the system.

Attend your son’s medical (and dental) appointments as much as possible.

Be prepared to fight. Push for his rights. (eg :Stephen’s bus pass)

Your position as an advocate is strengthened hugely if you had Power of Attorney. (See Appendix/Power of Attorney) It is not otherwise easy to break through the tight wire of bureaucracy and even then it can be difficult.

Appendix

I have put together an information pack covering what is at present available with respect to state and ancillary benefits. Some will not be relevant to you at this stage but it may be useful to be aware of their availability for the future.

Very often we can be unaware of what is out there. There is a money saving objective with most if not all local authorities, consequently, many benefits are not promoted and many are treated so restrictively that they are difficult to reach – and then we have to find out for ourselves and be assertive!

Benefits

There are many benefits available but accessing them is not always easy. Never hesitate to challenge.

A useful guide is [www.mencap.org.uk/benefits](http://www.mencap.org.uk/benefits) or phone your local Mencap office. Phoning and speaking to someone can be very helpful.

Employment support allowance (ESA) – a benefit paid to people whose ability to work is limited by either ill health or disability and who would otherwise seek job seekers’ allowance (JSA). ESA is paid at different rates depending on your circumstances and there is a 13 week assessment phase for all new claimants.

Personal independence payments (PIP) – this is replacing Disability Living Allowance(DLA) which is being phased out. Everyone who is on DLA is being reassessed for PIP.

The changeover procedure is as follows:

* Form filling – one form of several pages. Answer the questions painting the worst scenario.

eg: Question: Does he need help to wash or shower?

Answer: Can wash and shower himself but has to be reminded daily.

* Interview – accompany your son or have him accompanied by someone who knows him very well. Request beforehand that the interview be recorded. (You will have to take the equipment and you will be required to provide 2 recordings – one for you and one for the authorities)
* Appeal – if the outcome is unsatisfactory, you can appeal. Ensure that you get written support from your GP and any other professionals involved with your son. Present the case as strongly as possible referring to the interview recording where you felt that the questions were ambiguous and the answer, therefore, needed greater clarity.

If a situation goes to tribunal, you can have additional support from Mencap.

A summary of PIP:

* Between 2015 -2018 everyone aged between 16 -64 will have to apply for PIP rather than stay on DLA.
* PIP is a benefit for people who have mental or physical disability and need help participating in everyday life or find it difficult to get around.
* PIP is tax free, is not means tested, and you don’t pay national insurance contributions to be entitled to it.
* PIP has a care component and a mobility component and both components have two levels – a standard rate and an enhanced rate.
* PIP has no equivalent to the lower rate care component of DLA so fewer people are entitled to PIP.
* PIP is decided on how your illness affects you and what help you need rather than on diagnosis.
* The rate you get is based on specific things called ‘descriptors’ and uses points system.
* You need 8 points to get the standard rate and 12 points to get the enhanced rate for care/mobility.
* It is a good idea to get supporting evidence from your doctor, social worker, care worker and other professionals.
* The most useful evidence will explain how your illness or disability affects you and the help you need.
* The best evidence will come from people who know you well and who understand your situation.
* You could keep a diary of the help you need each day to give a proper understanding of your situation, especially if your condition is variable.
* Don’t be tempted to make light of your difficulties. Even if some of the issues are embarrassing it is important that they understand how your condition really affects you.
* There is a PIP self test link:

<http://www.benefitsandwork.co.uk/personal-independence-payment-pip/pip-self-test>

* If you need to appeal a decision you need to act quickly – you have one month from the date of letter they sent you to appeal.
* If you need more time phone the DWP and ask for an extension and a ‘statement of reasons’.
* If you can, see and advisor (CAB contacts above). There is a huge amount of unclaimed benefits (which you never hear about in the news).

Three useful websites are:

<https://www.citizensadvice.org.uk/about-us/how-we-provide-advice/advice/>

<https://www.tun2us.org.uk>

<https://www.mencap.org.uk/advice-and-support/benefits-people-learning:disability>

Employment and Support Allowance (ESA) (see www.gov.uk/ESA)

ESA offers:

* Financial support if you are unable to work
* Personalised help so that that you can work if you’re able to.

A Work Capability Assessment will place your son in one of two groups:

* Work-related activity group where there will be regular interviews with an advisor.
* A support group where you don’t have interviews.

Disabled Facilities Grant (see [www.disability](http://www.disability)rightsuk.org/housing)

You can apply to local council (Health and Service Trust) for adapting your home for a disabled person. (Applies only to England and Wales: varies from county to county and requires recommendation from OT and usually contribution to cost)

You will need to provide supporting evidence from your GP or OT or other appropriate professional.

* Outgoings (rent
* Council tax bill

Disability premiums ([www.gov.uk/disabilitypremium](http://www.gov.uk/disabilitypremium)/overview)

To qualify for these your son must be receiving DLA/PIP, Attendance Allowance or Incapacity Benefit.

To check eligibility use the Benefits Calculator (see below)

Carers’ Allowance (see [www.gov.uk/carers](http://www.gov.uk/carers)’ allowance)

* your son must be in receipt of DLA/PIP
* you spend at least 35 hours per week caring for him
* you yourself are not earning more than £116 weekly (after tax)

You will need to provide:

* Power of Attorney
* Proof of identification
* Proof of residency
* National Insurance Number

Housing Benefit (see Housing Benefit: Overview – GOV.UK)

* This does not apply if your son is living at home.
* It applies to private, council or social housing renting, providing it is bed-sit accommodation or single room in shared accommodation.
* Your son’s savings have to be below £16,000

Disabled persons Railcard (see disabledpersons-railcard.co.uk)

* Reduces travel cost by one third.
* An accompanying adult also gets a one third reduction

Community Alarm (see community alarm – GOV>UK)

* These are monitored 24 hours a day.
* There is a charge which varies from area to area
* Can be worn discreetly on the wrist or as a pendant.

Blue Badge

You qualify to have a blue badge if you are in receipt of PIP and have scored more than 8 points in your mobility assessment.

Disabled person’s bus pass (England only but may

* Application to local council for form (England) or Post Office (Wales, Scotland, Ireland)
* Some questions are ambiguous so don’t be afraid to add detail next to the ‘ticky boxes’!
* Present the worst possible scenario in your answer

Appointee for someone claiming benefits (see www.sense.org.uk)

An appointee is a person appointed by the Department of Work and Pensions (DWP) or local authority to receive welfare benefits on behalf of someone else. It is usually awarded where there is mental incapacity.

NOTE: If you are already an Attorney, your legal status is different to that of an appointee but managing someone’s benefits is generally the same. (England and Wales)

Benefits calculator

If you want someone to assess what benefits you can claim contact ‘Turn to us’

You will need information on:

* Savings
* Income
* Existing benefits/pensions

Advocacy

Advocacy is a very important part of future planning. Most xxyy men will need advocacy. They will need the support and direction that advocacy allows. There needs to be someone to be aware of anything available to help them; filling in forms correctly, a second voice at medical consultations and treatment, support to socialise, to find occupation, to arrange companionship for holidays etc:

We have to remember that most medics and other professionals your son will come into contact with are not going to have an understanding of the symptoms of 48xxyy. The professionals themselves will need information to make correct decisions. An advocate is needed to provide that written information at every step of the way in order to receive the best attention.

When your son has an appointment with a professional he has never met before, it is advisable to send in details of 48xxyy prior to the appointment.

Use every mechanism possible to present the facts.

Lasting Power of Attorney

There are two types of lasting Power of Attorney and it is advisable to have both.

Your support worker, Mencap or citizens’ advise bureau would advise you on a solicitor who specifically deals with a power of attorney for learning disabled. The fee is usually less and is often set up as a charity so that the fee is actually a donation.

Useful reference: communitymencap.org/lasting power of attorney

* Property and Financial Affairs for decisions on finance relating to a person’s bank account, investment or property.
* Health and Welfare for decisions about a person’s welfare and health. Where to live? What care or medical treatment should be received. Consent to life or sustaining medical treatment but only if the capacity to make relevant decisions has gone.

Have copies of your lasting power of attorney at hand. They can be useful where hospitalisation may occur and decisions have to be made or in any situation where your influence may be questioned. Ensure that your son’s GP and social/care worker and anyone else he may see regularly has a copy themselves.

Work

Programmes and grants to help you are:

* Work Choice (www.gov.uk/work-choice)
* Specialist Employability Support ([www.gov.uk/specialistemployability](http://www.gov.uk/specialistemployability)-supportproviderguidance)

Specialist employability support is for unemployed disabled adults with multiple or complex barriers preventing them from finding work.

Work Choice is delivered by public, private and ‘third sector’ providers

(see [www.gov.uk-work](http://www.gov.uk-work) -choice provider guidance/post April2017)

It is accessed via the Job Centre but your support worker should be able to do that for you.

It provides:

* Training and developing skills up to 6 months
* Help to start work and stay in your job for up to 12 months.
* Building your confidence
* Interview coaching

Support at work

Refer to wwwdisabilityrightsuk.org/access to work.

Also speak to someone at Mind UK. Telephone 03001233393.

Access to work grant – can give support to someone able to work more than 16 hours per week but who has a recognised disability.

* practical support
* special equipment
* Communicator at a job interview
* Fares to work if you can’t use public transport
* Disability awareness training for your colleagues
* Cost of moving your equipment if you change location or job
* Adaptations to equipment

How work affects benefits:

If your son receives the Employment and Support Allowance (ESA) he can take on ‘permitted’ work which would allow him to try out work within certain limits. Provided he works within these limits, his benefits will not be affected. The limits are:

1. Permitted lower limit

* you cannot work for more than 16 hours per week and any change of circumstances needs to be notified to the DWP.
* you cannot earn more than £20 per week.
* there is no limit on how long you can do a particular type of work so long as earnings remain below £20 per week.

1. Supported permitted work

* that the work is carried out as part of a treatment programme under medical supervision as an inpatient or outpatients of a hospital or similar institution.
* that work is done under the supervision of a person employed by a public or local authority or voluntary or community-interest organisation that provides or arranges opportunities for disabled people. The support must be ongoing and regular but the frequency of contact can vary depending upon the needs. Means of contact can be face to face or on the phone. It is important to check with the DWP that it counts as supported work.
* There is no limit as to how long you can do this type of work but your earnings should be no higher that £115.50 per week.

1. Permitted work higher limit:

* This is designed to test your ability to return to work before you move permanently into employment.
* If you are in the ESA support group you can earn up to £115.50 per week provided you work less than 16 hours per week.

Housing

Part of growing into adulthood is wanting independence which can mean that the option of living at home is no longer viable though some support is still needed. Arrangements are usually made through a support worker.

A useful site is www.disabilityengalnd.org.uk/resources

Options are:

* Renting from the local council or housing association. To do this you first have to register your interest and apply for property.
* Renting accommodation from relatives. (perhaps a family investment)
* Shared ownership with a housing association
* Buying a house using Support for Mortgage Interest.

(see [www.learning](http://www.learning)disabilityengland.org.uk/SMI)

* Renting from a private landlord
* Buying to let – sharing a property with you as the landlord.
* Shared lives where you live with a family other than your own where there is a carer within the family.
* Supported housing where you share a property with staff at hand.
* Living in a community for learning disability such as Camphill Trust centre. There are Camphill Trust communities throughout the country.

Money Management

Most banks offer ‘money management’ guidance but they are only advisory. Your son may find it difficult to abide by the advice!

A suggested process which can be part of the Care Plan:

* a joint account into which benefits are paid at a bank difficult to access.
* a separate one in your son’s name, easily accessible and into which two payments per week are fed to cover weekly outgoings plus some ‘pocket money’
* Any additional financial need to be accessed by parent
* All bank statements to be signed by both account holders.

Direct payments should be set up to avoid unnecessary handling of monies that are paid on a regular basis.

Trust funds – planning for the future

Useful contact [www.mencap.org.uk/wills](http://www.mencap.org.uk/wills) and trusts or telephone 02076966925

Mencap also holds local seminars. Check for dates in your area.

A lump sum inheritance paid into a Trust fund does not affect state or local authority benefits.

A ‘letter of wishes’ puts into writing your choice of use for the money in the Trust, however, that can be overridden by the Trustees. Choosing Trustees with your son’s best interest at heart is important.

2 types of Trust:

Discretionary – a beneficiary only has the right to claim at the discretion of the Trustees. There may be more than one beneficiary.

Disabled Person’s Trust – the main beneficiary has to be the disabled person. It can only be set up for the person if they are in receipt of PIP.

Other Useful Links

<http://aspirationsforlife.org>

[www.preparingforadulthood.org.uk](http://www.preparingforadulthood.org.uk)

<http://odi.dwp.gov.uk/odi-projects/jobs-for-people-with-learning-disbalites/project-search.php>

<http://weconnectnow.wordpress.com>