Rett UK

# Finding a way Through Transition

A parent carer resource produced by Rett UK with grateful thanks to

BBC Children in Need

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# Foreword

When my daughter Beth was very young and transition seemed a world away from all the immediate stresses and hurdles involved in caring for a severely disabled child, the "T" word still filled me with dread.

As Beth approached 16 years old, despite me asking about transition in my local authority area, nothing had commenced. I felt blessed at that point to hear from Rett UK that they had secured Children in Need funding for a project which could really make a difference, not just to our family, but many others like us. And it really did make a difference to us. A massive one.

Rett UK whose knowledge and experience of what was to come was outstanding. This was invaluable in meetings with my local authority where I was able to challenge what was happening with what "should" be happening in terms of best practice. I would never have had the confidence to do this without the preparation with the team and knowledge they had passed on to me.

One of my biggest frustrations as a parent of a disabled child is how to challenge those who know the system inside out when you do not know what you do not know! So many disabled children and their parents/carers lose out as the "system" ruthlessly sweeps them aside.

I would say one of our greatest challenges during transition was to try to secure appropriate funding for Beth which would enable her to access more suitable and varied care facilities and activities; vital to meet her complex health and emotional needs. The entire family was at breaking point when we first got involved with the project as drastic cuts to Beth's care package and we were exhausted and ground down trying to challenge the cuts. Beth's health and emotional wellbeing deteriorated during this period also.

Rett UK also got involved at this stage and helped us with funding applications and the myriad of criteria to fulfil. It is deeply frustrating and upsetting when your child overwhelmingly meets the criteria, but you still must overcome challenge and rejections along the way.

Beth has been up and running with adult services since her 18th birthday on March 17th, 2018. I have no doubt whatsoever that the fantastic and unwavering support of staff at Rett UK via this project were instrumental in that.

I do hope other families will be able to take advantage of this project in future, ideally as soon as their child is 14 years old. In my experience, these things take time due to the numbers of people involved and the various challenges along the way. However, if you put the effort in up front and take advantage of the support available via this project, the transition will be so much smoother.

We would have been lost without this project and the staff at Rett UK.

Thank you for helping to secure a better future for Beth

## Introduction

With the advancement in medical treatments, young people with complex needs are living longer including those with Rett syndrome. Survival into the fifth decade is typical in Rett syndrome with more than 70% of individuals surviving into middle age. However, there are some unexpected and unexplained deaths in younger ages.

Here at Rett UK we know that young people with Rett syndrome often struggle to have their needs addressed and planned for. Young people deserve to enjoy a happy and fulfilling life as possible, with opportunities and aspirations the same as their peers.

Many parents are often not aware what the future may look like but assume that once their package of care is in place, their son/daughter is in full-time education, having respite care services regularly, robust therapeutic interventions and their health need provided by professionals that know them, this will continue for the rest of their lives. Which in an ideal world would be the case, however the reality is the process of moving these support and care services from children's service to adult services, can be quite a complex and challenging experience.

Families whom we have supported through this transition, have told us if only they had realised much earlier on in the process about the things that would be likely to change and how their influence and wishes would play a big part in the process, things would have been very different.

We want to provide a resource for young people and their families, which will guide them through transition, help them understand what that process may look like, but also to provide them with clear information that empowers them to get the best possible outcome for their young person.

Changes to the Special Educational Needs and Disability services for young people, which saw them being moved away from 'Statements' and onto Education Health & Care Plans means these can be in place up to the age of 25 years in England and similar changes in Scotland, Wales and Northern Ireland give an opportunity to experience a more integrated approach to transition.

However, the 2014 Care Quality Commission report "From the Pond into the Sea" show that young people with complex health needs do not always receive the care and support they need when they move on to adult care services.

Here at Rett UK, we see first-hand how the pressures on social care funding is having an impact on young people and their families, even before the pandemic and with more cuts expected, getting a satisfactory level of support is going to be even more difficult, with more emphasis on demonstrating the need. It may be beneficial to consider using a direct payment, which can provide more flexibility to use what may be a smaller than expected budget, to tailor the care package to the wishes and aspirations of the young person with Rett syndrome.

Alongside that, many young people with Rett syndrome may qualify for Continuing Health Care funding through the NHS and may benefit from the expansion of Personal Health Budgets, which can be used in a similar way to social care direct payments giving the young person and their family more choice about where and how the care is provided.

This booklet is designed to give you all the information you need about navigating through transition with your young person, providing a timeline of information about what ideally would be happening and at what age, displayed across our centre-page spread. More in-depth information is to be found in the sections Preparing for Adulthood, Preparing for Moving on and Settling into Adult Services.

## What do we mean by transition?

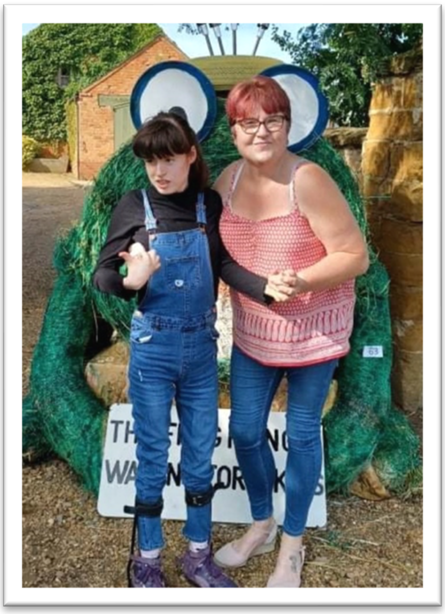
Young people with Rett syndrome will experience different types of transitions in their life. Young adulthood is a distinct phase.

It is important to consider the needs and aspirations of young people with Rett syndrome in line with adolescence. Over the past 50 years our understanding of the sociology, social, developmental, and educational psychology of young people has become clearer and there are good descriptions of the development stages that young people experience during phases of adolescence.

Some things to consider are outlined in the table below.

| | **EARLY ADOLESCENCE**<br>*12-14 years (females)*<br>*13-14 years (males)* | **MIDDLE ADOLESCENCE**<br>*14-16 years* | **LATE ADOLESCENCE**<br>*17-24 years* |
|---|---|---|---|
| **KEY ISSUES & CHARACTERISTICS** | Focus on development of body<br>Pubertal changes occur<br>Rapid physical growth<br>Mood swing & temper tantrums<br>Daydreaming | Sexual awakening<br>Emancipation from parents and authority figures<br>Discovering limitations by testing boundaries.<br>Role of peer group increases | Defining and undertaking roles in life,<br>• Careers<br>• Relationships<br>• Lifestyles |
| **SOCIAL, RELATIONSHIPS, BEHAVIOURS** | Improved skills in abstract thought<br>Ability to acknowledge consequences and future planning<br>High energy levels<br>Appetite increases<br>Social interaction in groups<br>Membership of peer groups important | Relationships are self-absorbed<br>Risk taking behaviours may increase<br>Intense peer interaction<br>Most vulnerable to psychological problems | Increasing financial independence<br>Planning for the future<br>Developing of permanent relationships<br>Increasing time spent away from the family |
| **IMPACT OF RETT SYNDROME** | May be concerned about their physical appearance and/or lack of mobility<br>Privacy becomes more important<br>Impact that Rett syndrome may have on cognitive development or learning, (school absences, medication, pain, depression, fatigue)<br>Ability to compare with peers may be difficult<br>Lack of acceptance by peers<br>Reliance on parents and carers for decision-making<br>Impact of hospital admissions of concern | Symptoms may increase during adolescence, such as increase in seizures<br>Impact of growth on scoliosis<br>Ability to develop independence from parents & professional may be difficult<br>Dependence on family for companionship and social support. | Lack of opportunity for independence<br>Reliance on parent and carers for financial management<br>Difficult to form independent relationship |

## Issues for young people with Rett syndrome



As a young person with Rett syndrome moves into adolescence, they may develop their own ideas, views, and aspirations about their future. Although for someone with Rett syndrome it may be difficult to communicate this to those around them. However we should not assume that they do not have the same priorities as their peers, and they should be supported to express their wishes, thoughts and feelings using their preferred and most accessible communication method. Things to consider should include:

- Opportunities for some independence
- To be able to develop friendships
- Build relationships
- Have access to information in an accessible format
- Further education opportunities, such as specialist colleges
- Guidance about housing options
- Involving the young person in planning and decision making
- Short breaks and respite, holidays, fun and leisure activities
- Access to appropriate transport

Young people with Rett syndrome, may require a lot of support to achieve their life goals and for whom total independence may not be achievable. However, the young person should be supported and involved, to communicate their future aspirations, be part of the planning ahead using a person-centred approached to allow them to develop emotionally, physically, and socially, to lead fulfilling lives in which they are supported to achieve their ambitions.

## Issues for parents

Parents of a young person with Rett syndrome will play an active part in enabling the young person to be supported in adulthood and there are some key issues that families have told us they have had to struggle through.

The lack of a joined up person-centred approach across all areas, when planning where multiple agencies are involved, the difficulties in getting everyone around the table at the same time.

The lack of understanding by many professionals of a complex genetic disorder such as Rett syndrome, again impact of the parents having to explain about the condition to everyone involved.

More opportunities and the time for the young person to be involved in their meeting and the planning process in general. Having information readily accessible to the young person as well as ensuring they always have the support of a communication partner.

Ensuring that all professionals listen to the young person and their parents.

“Being able to run my thoughts and ideas past the Rett UK family support officer has reassured me, provided me with confidence that I am on the right track and given me the hope that what I want for my daughter could become a reality. I am also grateful that Rett UK are supporting me in every step of the way and offer me the advice to make sure professionals are accountable.” Natalie, mum to Chole aged 19.

## Issues for siblings

Siblings often undertake a role of carer within the family unit, alongside their parents and as their sibling approaches adulthood the demand of them may become higher.

Siblings may find the transition journey an emotional time and may also struggle to understand what is happening to their brother of sister, and the impact that this is having on their parents. They may try to minimise their own needs or may assert them more loudly to get their parents attention.

It may help to speak and prepare the siblings for the changes in the dynamics within the family and this should be part of the planning too.

Some key issues that siblings have spoken about, and should be considered:

- Being able to be 'just a sibling' to the young person with Rett syndrome, and not having to be part of the caring, but also to be recognised for their unique relationship they will have with their sibling, this knowledge and experience can be included in the transition process.
- The sibling may also be experiencing transition within their own lives and be experiencing changes to their lives, such as maybe leaving home to go to university or 'moving on' into work or living outside the family unit.
- Access to information about their own rights as young carer, including opportunities to promote their wellbeing. There is some great information for both siblings and parents on the Siblings website https://www.sibs.org.uk/

## Financial issues

You normally have to be aged at least 18 to claim Universal Credit, but special rules allow 16 and 17-year-olds to claim if either:

- they are submitting medical certificates from their GP, or

- have established that they have a limited capability for work.

If you choose to claim Universal Credit on behalf on behalf of your daughter/son, this can affect the benefits that **you** receive. They will stop being treated as a dependent child of yours and this means that Child Benefit, Child Tax Credit or other payments that you receive for them as part of your family will stop, so you may need advice about which to claim, or you can research the amounts involved. You can look at the different benefit amounts which would be paid depending on who claims by using an online calculator like the one on the website Turn2Us.

Even if your young person claims Universal Credit, you can still be their appointee for the benefit, if that is necessary (that means you would be responsible for making the claim and reporting all changes of circumstances).

In some parts of the country, a young person claiming income-related ESA may be required to claim Universal Credit (UC). If there is no change of circumstance for the young person, they do not have to claim UC.

However, if there is a relevant change in their circumstances (i.e., one which necessitates a fresh claim) they may find themselves coming off ESA. This is called 'natural' migration to UC. Eventually, everyone currently on ESA will be moved over to UC - called 'managed' migration, but this has not started yet.

For those who naturally migrate to UC there is no protection of their current rate of benefit, if the person on ESA gets a severe disability premium, they may get partial protection. Some may find that they are better off under UC, primarily those who are in the 'support group' as the amount given is more than the equivalent in ESA.

Those who are eventually moved under 'managed' migration should get help with the loss of the severe disability premium, but not the other premiums/component.

There is a wide range of disability-related financial support, including benefits, tax credits, payments, grants and concessions.

Contact have a really helpful factsheet about claiming Universal Credit for your young person universal_credit_young_person.pdf (contact.org.uk)

### Some benefits you may be entitled to are:

Universal Credit - www.gov.uk/universal-credit

Universal Credit is a payment to help with your living costs. It's paid monthly - or twice a month for some people in Scotland.

You may be able to get it if you're on a low income, out of work or you cannot work.

Personal Independence Payment (PIP) or Disability Living Allowance (DLA) –

For more information on Universal Credit and the different types you can claim see the GOV.UK guidance

This website has some great information about further education for children with disabilities

https://www.disabilityrightsuk.org/funding-further-education-disabled-students

# The Transition Journey

## Phase 1

## Preparing for Adulthood

### *Introduction – summary of what should happen at this phase*

“Transition was regularly described to me by other parents, and even professionals, as an overwhelmingly stressful time for the entire family. The reasons behind this varied. Transition could be a postcode lottery of variable quality. It could also be an opportunity to withdraw funding and services. The process was always started too late. Whatever the reason, Transition inevitably seemed to result in little or no choice for the disabled young person.” Val, Mum to Beth aged 19,

It is an accepted principle that the transition process should begin around the age of 14, with the first conversations about it being had during the year 9 Annual EHCP Review meeting. Here we describe the steps necessary to begin the process. The key to a successful transition is everybody acknowledges that it is the start of a new phase for the young person, a time to move on, new people and new places. This is especially hard for the parents of young people with Rett syndrome. With such a complex, rare disorder it takes time for people to fully understand the needs of the young person and for the parents to feel confident about entrusting the care of their young person to someone else.

Each transition will be different. There is no one size fits all and as transition should span several years, it is likely that there will be changes along the way and adjustments need to be made to the original ideas and goals.

Taking a proactive and positive approach with early introductions to adult services, exploring what is on offer in your area and talking to other parents of young people with similar needs is extremely helpful.

Without exception, young people with Rett syndrome in England will have an Education Health and Care Plan (which replaced Statements of Special Educational Needs under the Children and Families Act 2014). In Scotland, the similar document is a Co-ordinated Support Plan. In Wales in 2017, the equivalent document became Individual Development Plans (IDPs) which have to contain a description of the need and provision. In Northern Ireland, they are still using Statement of Special Educational Needs but they all take a similar approach in as much as these should be a person centred, outcome focused plan with coordination of services provided by  health, social care and education. These plans form the cornerstone of the transition process.

### Key Aims During Phase 1

- Your young person is very much at the centre of planning and consideration has been given to how to facilitate their meaningful involvement, using their preferred method of communicating supported by a communication partner.
- Initial conversations about transition take place with the young person and their family at the Year 9 Annual EHCP Review meeting
- There is a follow-up meeting with the young person and family. This should not be left till the Year 10 review.
- The first multi-agency/multi-disciplinary team meeting takes place.

## Case Study:

Bex turned 18 in January 2021, so our experience is recent.

We have been an independent family, choosing not to use support services apart from some regular respite, prior to this service closing. We never had a social worker but always saw the same social work support assistant every six months. Like a lot of families, we have been mostly self-sufficient and just got on with it.

Bex attended a specialist school (outside of our LA area) where she received fulltime 1:1 support and all therapies were on site. It also has a college and further provision after college. These establishments offer a wide range of services to children, young people and adults and meet the needs of disabled people with communication impairments, sensory impairments and complex learning, social care, and therapeutic needs.

The word 'transition' kept popping up in annual reviews, especially EHCP. As the words 'best interests' started to become more frequent in conversations, feelings of dread emerged. We had heard of other parents' experiences and how it had felt like dropping off a cliff. So, we actively planned to make sure that that did not happen to us.

It was important to try to develop a good transitional relationship between Children's Services and Adult Services. For about 12 months prior to official handover, we had dual meetings both with Children's Services and our allocated Adult Services Social worker.

We provided the social worker with as much information as we could – EHCP, all relevant Rett Syndrome information, 'All About Me' booklet and advocacy statements from Rett UK.

Our long-term plan was for Bex to attend College and afterwards, our longer-term plan would be for Bex to have some independent supported living with wraparound care 24/7, the full package. We had already done our own research regarding various supported living establishments around our area.

The social worker compiled a care plan for Bex. We read it very carefully and sent it back for amendments. We ensured they were aware of the increasing therapeutic needs, Bex requiring a minimum fulltime 1:1 support and her epilepsy. These threads ran throughout the care plan.

Once Bex turned 18, we were officially discharged via a letter from Children's Services.

As plans were being made for Bex moving on from school, the SEN Post 16 Education Panel suggested that if we wanted Bex to continue her education then they would agree for Bex to attend 3 days of education at a specialist college which was still within the organisation we were already in. Social services would provide 2 days social care. The course that Bex was offered a place on is an integrated course which covers both education and social care. It is all on one site, with the same facilities, therapists and personnel covering all aspects of the course. For years, this is the way it has been, and we assumed that we would follow the same path.

Shortly afterwards, we were notified of a meeting with our social worker. Out of the blue, she asked us to look at day care provision in our local authority area. This completely threw us as we knew that previous students had already gone through the original set-up. She gave us a list of 4-day care centres for us to look at and consider. Luckily, we had been informed about some recent legislation of the Children and Families Act (2014) and the contingencies of section 3 of the Special Educational Needs Codes of Practice 2014. This includes section 3.1 and 3.13 of the latter which state –

*Section 3.1 SENCOP* - Section 25 of the Children and families Act 2014 places a duty on local authorities that should ensure integration between educational provision and training provision, health, and social care provision, where this would promote wellbeing and improve the quality of provision for disabled young people and those with SEN.

*Section 3.13 SENCOP* - Local Authorities MUST work to integrate educational provision and training provision with health and social care provision where they think that this would promote the wellbeing of children and young people with SEN or disabilities or improve the quality of special education provision. Local partners MUST co-operate with the local authority in this. The NHS Mandate, NHS Act 2006 and Health and Social Care Act 2012 make clear that NHS England, CCGs and Health and Wellbeing Boards MUST promote the integration of services.

Unsettled by this request for an unexpected meeting, we had already undertaken additional research, which allowed us to inform the social worker that what she was doing was completely wrong and breached the Codes of Practice, and in fact, what they were doing was breaking the law and that we would challenge them at court. We asked her to provide written reasoning for their unlawful requests and decisions, which was not to fund the social care aspects of the placement at this specialist college. In fact, the following day, we received an email from the social worker asking us to look at every day care centre within our local authority! A total of twelve different establishments. Not one day care centre within our local authority would be able to meet Bex needs. Then, within three hours of receiving that email, the social worker called us stating that they had good news and that Bex would indeed be able to attend the integrated college course after all. Despite being promised a response from her line manager explaining their initial decision-making process as to why they thought Bex attending the five-day integrated course was not in Bex best interests, it has never been received. Bex started college on the 5-day integrated program in September 2021 and has been thriving. In fact, her tutor commented that she looks like she has always been there.

The battle for the first year of the college course is won. However, even though it is a two-year course, we still need to evidence on-going progression and stretch to be allowed to attend the second year.

On a good note, after college was sorted, we were fully prepared for a fight to obtain college transport but that was surprisingly painless.

As a family, we suffered a great deal of unnecessary stress from our social services. We thought they were there to support us, not work against, and in our opinion, try to bully us into an outcome which would not have been in Bex best interests, and was simply a cost cutting exercise. After a huge battle with social services, Bex has ended up exactly where she should be, on a fully integrated course and which meets all her needs.

It shouldn't have been as difficult as this.

Health - We have been fortunate to have kept the same Consultant Paediatrician throughout Bex journey. We also knew that we needed to identify which one of our GPs would become responsible for Bex care once she went into adult services. Again, we were fortunate to link in with a GP who had been trained up by our Consultant Paediatrician and so they have worked very closely together. Our Consultant Paediatrician organised a joint Teams meeting with our GP to discuss moving forward. We had a long think about this before the meeting and drew up a list of questions and concerns, e.g., what happens with epilepsy appts and what if we need to speak with someone sooner, what about orthotics etc. I then dropped off a copy of the Rett Disorders Alliance Health Checklist for our GP. Rett Disorders Alliance Health Checklist (rettuk.org)

We are currently somewhere in the middle of Paediatric appts and adult services appointments.

When Bex was younger, we applied for Continuing Health Care (CHC) funding, but we were turned down. However, as adulthood approached, we applied again. This time, we had a full team of therapists, social workers, and advocacy statements from Rett UK, behind us at the meeting.

This time, Bex was awarded full CHC.

### Our Top Tips for Transition:

- Do not be persuaded to change your minds by social workers, stick to your guns.
- Question everything, accept nothing at face value
- Think and plan ahead
- Do your research
- Ensure care plans include everything you need
- Obtain Deputyship for health and welfare. I would seriously consider it. As soon as we told our social worker, it seemed to take the wind out of her sails and clearly put us in a far stronger position to argue the case on behalf of Bex. It has smoothed the way for us with regards to adult healthcare and we have already applied it to dentistry, podiatry, and GP services.
- Familiarise yourself with relevant legislation
- Contact Rett UK for help and support. They are a great resource and very supportive. They have provided us with advocacy statements for our EHCP and Care Plan. We have had zoom meetings with Rett UK about Transition, Independent Living, Funding for Care and Support Services and Deputyship amongst others. All of these have been invaluable to us when transitioning to adult services.

| Annual Review | Preparing for Adulthood Young person aged 14+ | Preparing for moving on Young person aged 14 – 18 | |
|---|---|---|---|
| Health | Initial conversations begin to take place about transition with the young person and their family.<br>It is now a good time to begin to liaise with the GP and young person, in readiness for transfer from paediatrician.<br>Access to therapists may be more difficult in adult social care, consider current and potential futures needs.<br>If not currently part of the EHC plan, they may need to be incorporated, in order to help with on-going provision of therapeutic interventions. | Following an initial assessment of the young persons need, a care plan will be written up, the funding for this will then be agreed between Social Care and Health.<br>The young person may be funded through Continuing Health Care, particularly if their needs are complex. A personal health budget is a flexible way of using that money to pay for support staff and the services the young person may need.<br>If the young person is not funded through health then their local Adult Social Care Department should fund their support needs.<br>The GP is now the first point of contact with regards to health needs, unless the paediatric care has been handed over to an adult health consultant, such as for management of epilepsy or other on-going conditions. | Once plan<br>An a that care<br>The inclu popu press chec<br>Refe is ne othe |
| Social Care | A transition social worker may be allocated to attend annual reviews. | The young person may be funded through the social care budgets, following the community care assessment of needs. Social care will be able to help with home care services and support. It may be worth considering a personal budget/direct payment which will allow the care provided to be more flexible, with the use of person al assistants.<br>Social care can also arrange for adult respite or short breaks services. | An a that care<br>It ma Liber restr com takin , as e |
| Education | It is the responsibility of the school to co-ordinate the discussions at the 14+ transition review.<br>Social services representatives should be invited and ideally a transition social should attend the meeting<br>Health professionals, including therapists, involved in the young person's care should also be invited. | The annual review meeting should now be transition focussed and reviewing the transition plan to meet the needs of the young person and should include health and social care professionals and therapists<br>Young people and their parents may wish to look at and consider specialist adult education colleges, in their local area that can meet the needs of the young person. Local colleges will be listed on the local authority website, under the Local Offer section. If you consider that the local colleges are not suitable, then the young person may consider going further afield or possibly a residential college. Specialist colleges can also be found at www.natspec.org.uk | Your help usua by a the y |
| Housing | The young person is likely to be living at home with their parents, is this likely to continue beyond 18 or may consideration be given to moving into residential care of supported living. Ideally now is a time to start considering this for the future. | If the young person and their family are going to consider residential care of supported living, now is the time to start looking at suitable places in the local area. The local authority will list these on their website under the Local Offer or you may wish to look at the CQC (Care Quality Commission) https://www.cqc.org.uk/ . The website provides the opportunity to search all registered services and view their inspection reports. | If a y their of ho Shelt com able area |
| Well-being & Leisure | Does the young person attend any clubs or undertake activities? Will these continue once they turn 18 or will other activities need to be considered? | | A nu peop https |
| | The young person may be in receipt of a number of benefits, such as child benefit and DLA or PIP, parents may also be in receipt of Child Tax Credits too. For a review of | When the young person turns 16 they will be entitled to claim ESA in their own right, this can be beneficial as it gives access to a bursary which may be used to purchase adult education provision. However, consideration | Once finar pers |

### *Aim 1:* Putting your young person at the centre of all discussions about them

When it comes to person centred planning, the person must be the focus of all discussions, they should be consulted throughout the planning process, and they should be able to choose the setting and the timing of the meetings. For parents of someone with Rett syndrome, this may seem idealistic and the likelihood of the young person and their family being able to dictate where and when the meeting is held is doubtful. Rett UK's advice would nevertheless be to aim for the gold standard, but the key point here should be that your young person is the focus, and they are supported throughout the process, so their feelings, wishes and opinions are heard and considered. The other critical point is having key people attending the meeting which is why you may need to compromise on where and when it is held.

With the involvement of friends and family, sometimes referred to as the 'circle of support,' person centred planning should be a process of continual listening and learning, finding out what is important now and is likely to be important in the future. It should facilitate problem solving, negotiation to make the most of available resources which will meet the young person's needs, whether those are from the 'circle of support' or from voluntary or statutory providers.

By including the young person every step of the way, you will help to increase their confidence and self-esteem but also, very importantly for people with Rett syndrome, reduce their anxieties. When the key people are involved from the start and they get to know the young person, they tend to be much more motivated and committed to meeting the needs and wishes of the young person.

Consideration needs to be given to how the young person with Rett syndrome will be able to participate. They already have access to a robust language system whether that is high tech using eye gaze technology, or low tech with a symbol-based system using partner assisted scanning or a well-established, well defined, yes/no response. If you would like more information about communication strategies for people with Rett syndrome please visit the web site or call the office for further advice.

### *Aim 2: Initial conversations take place about transition*

This should be an outcome focused meeting with key people involved. Thought needs to be given to who should chair the meeting; ideally someone who the family know and trust but who also has the authority to make sure things get actioned. Ideally, if the meeting can be held somewhere that is familiar to the young person. The tone of this initial meeting is important to everyone. Being positive ad accepting about the fact that change will happen but also feeling that any concerns you have as parents are taken seriously and acted upon is vital as it will lay the foundations for future meetings. As parents, you want to know what support is going to be available throughout the process, what resources are available locally. Minutes of the meeting must available shortly after the meeting and distributed to all involved, then a date should be booked for a timely follow up to address actions

If it is appropriate, the young person should be given the opportunity to meet the lead professional on their own or with an advocate (not necessarily a family member), but this should consider the communication and support needs of the young person. Every attempt should be made to give them the opportunity to raise concerns and ask questions.

### *Aim 3: A follow up meeting with the young person and the family should take place as soon as possible.*

This should allow for a review of initial discussions, look at where there are differences of opinion and areas that could be problematic. Consent should be given to share relevant information with key people who will be attending the first multi-disciplinary meeting and introduce the names of new people and their roles.

### *Aim 4: First Multi-Disciplinary Meeting Takes Place*

The chair for the meeting should have already been agreed and they are responsible for setting the agenda based on the discussions from the initial meeting. The young person should be supported to use their preferred method of communication. This could be using an eye gaze device, pictures, symbols and/or photos and these should be prepared beforehand.

The young person's key worker should be identified at this meeting. Some areas will still be able to offer a dedicated transition support worker and typically does fall to someone in social care, but the role could be fulfilled by a teacher or a senior carer from a residential/respite setting that knows the young person well.

Professionals involved should be able to leave the meeting with a clear idea of the young persons and the families wishes and be ready to take responsibility for their role going forward and in seeing those fulfilled. There should be a formal record of the meeting, with the minutes showing who is responsible for agreed actions and when they should be completed. A copy should be given to the family and the young person.

## Phase 2

### *Preparing to move on*

A momentum to the planning now needs to be maintained over the next few years with regular multi agency assessment meetings which should focus on how the different agencies involved will work together to meet your young person's needs. A multi-agency transition plan should be written up with everyone involved from children's and adult's services liaising to achieve a smooth transition.

The shift here should be from family centred care to young person centred. We recognise that is it hard for you as parents to let go. Hard for many reasons; years of battling to get yourself heard, to get the appropriate care and services for your daughter/son and years invested emotionally in being the person who holds it all together and knows your young person better than anyone.

Rett UK is here to support you through this and help you support your young person to grow in confidence and involve them in decisions which affect their future as much as you can.

### *Aim 1. Your young person and you are supported to make the shift from care coordinated and often delivered by the family to fit with family life to care that is centred around the young person as an individual.*

Your young person should be encouraged and supported to be involved in decisions about their future. For some young people it might be appropriate to have an advocate who can help them express their wishes without the fear of offending their parent carers. It can also lessen the risk of the young person being steered in one direction when it is not necessarily what they want to do.

Where there is a difference of opinion between parents and the young person, support from an external agency should be able to handle this sensitively so that everyone feels respected, listened to, and valued.

Everyone should also be conscious of the legal implications of the Mental Capacity Act; the changes it brings to decision making. Once someone reaches the age of 16 they must be assumed competent to make their own decisions. Clearly for many people with Rett syndrome this can be problematic – just how much does the young person understand? Some parents will have a clear view on this and will know what the limitations are etc. Being able to decide what they would like for dinner may not translate to being able to make an informed decision about where they want to live.

If it is agreed that the young person does lack capacity (and a formal assessment may be necessary by a trained social worker or GP), then professionals and the family need to make decisions on behalf of the young person based on 'best interests.' It should be noted though that whilst you as parents will be consulted, your views are not legally binding. You may find this challenging when you have had far more say when they were children.

## Court of Protection Deputyship

The Court of Protection is a superior court in England and Wales created under the Mental Capacity Act 2005. It decides whether a person has mental capacity to make financial and welfare decisions for themselves. If a person does not have capacity, the Court has the power to appoint a 'Deputy' to make decisions on that person's behalf.

If the person with Rett syndrome is over 18 and is does not have the mental capacity to make decisions for themselves, you may consider applying to the Court to become their Deputy so that you are legally authorised to make 'property and financial'

This could be about their medical treatment or how they manage their finances.

In terms of making any decisions about medical treatments or interventions, without the Deputyship, then there would need to be a Best Interest Meeting, involving parents, social workers, doctors, and any other people caring and supporting that young person. The Best Interest Meeting will decide what the course of action will be, this may differ from the parent's view, but they will go with the majority consensus of the meeting. The Chair of the Best Interest Meeting will have the final say and not the parent.

Parents can still legally be their Appointee in terms of managing any benefits, but they could be challenged about how that money is spent, and if the Local Authority felt the persons finances were being mismanaged, they could insist the benefits are paid into a managed account, again excluding parents from having any say in decisions about how the money is spent, if they do not have the legal responsibility that Deputyship affords them.

There are two types of Deputies, one to cover Health & Welfare, the other covers Property & Finance, you may wish to apply for both. Information about becoming and Duty and the relevant forms can be downloaded from the Government website: Deputies: make decisions for someone who lacks capacity - GOV.UK (www.gov.uk) There is also a really helpful webinar here from Rett UK which will answer lots of your questions.

The Court of Protection will set out the Deputy's specific powers in a 'Deputy Order.' The powers given will depend on the application and the needs of the individual on whose behalf decisions are being made. The power can relate to property and affairs, personal welfare, or both.

A Deputy must only make decisions authorised by the Deputy Order. It is essential that any decisions are made in the best interests of the individual and the Deputy must apply certain standards of care and skill when making decisions.

The Court of Protection will offer support to the Deputy and will provide supervision where necessary. Each year the Court will require the Deputy to submit a report explaining any significant decision and if the Order applies to property and financial affairs, a financial report is required.

To apply to the Court of Protection, you can complete the forms either on paper or online. Although you can complete the forms yourself, many people choose to instruct a Lawyer to prepare the application to avoid costly errors, confusion, and unnecessary delay.

https://www.gov.uk/become-deputy/apply-deputy

Additional information and a list of local law firms you can also visit https://www.mencap.org.uk/our-services/wills-and-trustsInfo about being an appointee for DWP

## Deprivation of Liberties Safeguards

The Deprivation of Liberty Safeguards (DOLs) are part of the Mental Capacity Act. They aim to make sure that people being cared for in settings such as care homes, hospitals, hospices, and supported living are looked after in a way that does not inappropriately restrict their freedom. These safeguards can be difficult for parents/carers as they can challenge the way that they have cared for their child over the years. For example, it may no longer be considered appropriate to use cot sides or video surveillance as the young person becomes an adult. It is important that robust needs assessment and risk assessments are carried out to ensure that appropriate levels of safety are maintained.

DOLS ensures people who cannot consent to their care arrangements in a care home, hospital or in the community which includes the family home, are protected if those arrangements deprive them of their liberty. Arrangements are assessed to check they are necessary and, in the person's, best interests. Representation and the right to challenge a deprivation are other safeguards that are part of DOLS.

## The Liberty Protection Safeguards (LPS)

The Liberty Protection Safeguards (LPS) will replace the Deprivation of Liberty Safeguards (DOLS), the date has been delayed on a number of occasions and is still to be announced, but it is good to know in advance what changes there may be. This was announced in a Mental Capacity (Amendment) Bill which passed into law in May 2019. Key features will include starting at 16 years of age, and deprivations of liberty having to be authorised in advance by the 'responsible body'.

Key features of the Liberty Protection Safeguards (LPS) include:

- Deprivations of liberty must be authorised in advance by the 'responsible body'.
    - For NHS hospitals, the responsible body will be the 'hospital manager.'
    - For arrangements under Continuing Health Care outside of a hospital, the 'responsible body' will be their local CCG (or Health Board in Wales).
    - In all other cases – such as in care homes, supported living schemes etc. (including for self-funders), and private hospitals, the responsible body will be the local authority.
- For the responsible body to authorise any deprivation of liberty, it needs to be clear that:
    - The person lacks the capacity to consent to the care arrangements
    - The person has a mental disorder
    - The arrangements are necessary to prevent harm to the cared-for person and proportionate to the likelihood and seriousness of that harm.
- To determine this, the responsible body must consult with the person and others, to understand what the person's wishes and feelings about the arrangements are.
- An individual from the responsible body, but not someone directly involved in the care and support of the person subject to the care arrangements, must conclude if the arrangements meet the three criteria above (lack of capacity; mental disorder; necessity and proportionality).
- Where it is clear, or suspected, that the person objects to the care arrangements, then a more thorough review of the case must be carried out by an Approved Mental Capacity Professional.

- Safeguards once a deprivation is authorised include regular reviews by the responsible body and the right to an appropriate person or an Independent Mental Capacity Assessor (IMCA) to represent a person and protect their interests.
- As under DOLS, a deprivation can be for a maximum of one year initially. Under LPS, this can be renewed initially for one year, but after that for up to three years.
- Again, as under DOLS, the Court of Protection will oversee any disputes or appeals.

The new Act also broadens the scope to treat people, and deprive them of their liberty, in a medical emergency, without gaining prior authorisation.

### *Aim 2: Your young person and you are supported to think about plans and aspirations for the future. These plans should be supported by a continuous multiagency assessment, ensuring that all support is centred around the young person as an individual.*

Your young person's ability to share their views and opinions will differ, but it is important that the young person is given the time and space to consider their options, utilising whatever resources are available to them. This is likely to be utilising Alternative Augmentative Communication (AAC) strategies including eye gaze devices, pictures, symbols, or photographs.

Each young person's ability to shape his or her own multi-agency plan will be different and the professionals supporting the young person have a duty to ensure all resources and opportunities have been utilised fully to empower and enable the young people have meaningful involvement in the planning of their care.

Ideally, it would be the role of the young person's key worker who would begin the planning process whilst the young person is still accessing children's services.

An assessment of the young person by all agencies to establish their level of need, should be provided by all agencies currently supporting them, this should be a joined-up process, so that any potential health needs are identified and included as part a wider transition plan.

As part of the Children and Families Act, 2014, healthcare assessments are now part of the young person's EHC Plan. If your young person has not yet been assessed for an EHC Plan, then this is now a priority to ensure that have an effective EHC plan in place, as it can shape their future health assessments too, particularly around their ability to access any ongoing therapeutic interventions.

Your young person should be encouraged to think about their future hopes and plans in several different areas, including further education, where they live, things they like to do in their leisure time, where they may like to live in the future and anything else in their life that is important to them, this would include friendship groups.

### *Aim 3: Your and your young person should be supported to choose the adult services best able to meet their complex needs.*

Sometimes services that the young person has been using whilst supported by children's services, may not necessarily be available within an adult service setting.

Ideally, children's & adult services should look for local services that are most suitable for your young person, and who will be flexible and responsive, to the potential fluctuating levels of support needs a young person with Rett syndrome may experience, and ideally maintain continuity of care during the transition period.

Continuing to use a person centre approach, by the multidisciplinary team, for your young person, means that their needs should remain the focus for all future adult provision, rather than just attempting to match like for like. Services may well be provided by entirely different organisations or agencies, within adult's services, however, with the appropriate support and training for their staff teams, they should be able to meet the needs of your young person.

Consideration should be given to how to enable your young person to move towards independence in adult services and it will require the care teams to support the young person with their health care needs in several different environments, which may include:

- Social services provided day provision
- Residential or day colleges
- Health providers
- Staff, such as PA's who may be directly employed by using either a direct payment or a personal health budget.

A support team should monitor your young person to identify if the following is in place

- Consistency in the staff teams providing support
- Staff to meet the needs of their specific package of care
- Is the organisation equipped to carry out more complex tasks such as gastrostomy feeding?

You and your young person may consider employing your own support staff, which would give more flexibility about the care and control of the care, in this instance the above would also be relevant to the individual employed. You should consider:

- What checks need to be undertaken prior to their being offered a position, such as DBS (Disclosure and Barring Services) clearance (this can be done through your local disability resource centre or your local authority may do this on your behalf), also consider references from previous employers or recommendations.

- How would the PA's access relevant training for them within their role, such as Manual Handling, Safeguarding Children/Vulnerable Adults, First Aid. It is the employer's responsibility to ensure this has taken place and regularly updated.

- What additional training may be required for the administration of medication or setting up PEG feeding, would they be able to be trained by local community nurses.

A greater emphasis is now in place on a young person (and/or their families) being able to steer the care and support directly, through having personal budgets, to enable more choice in the delivery of the support and care of the young person.

If this is something that you and your young person are considering, it is worth looking into potential pitfalls, that may also arise, by employing staff.

Such as,

- how would you cover sickness, holidays, parental leave, and any other staff absences?
- Is there a back-up plan, for any last-minute staff absence?
- Are there any potential hidden costs, such as staff training?
- Who will manage the payroll?
- Pensions will need to be considered too if you employ a PA
- How will you manage disputes?

For both social care direct payments and person health budgets there are third party arrangement agencies who could take on the employer role and managed the recruitment, training, and retention of staff, however there will be a charge for them to administer these services. Your local authority should be able to give you a list of agencies in your area who would undertake this role.

## Phase 3

*Settling into adult services*

### *Aim 1: A young person should be supported in adult services by a key worker, who will provide a stable point of contact co-ordinating care between children's and adult services*

It is usual practice once your young person moves into adult services that they will be allocated a named keyworker, to provide a point of contact and who will be able to co-ordinate the care provided by various the service providers and agencies. If you have any questions about your young person's, support or care needs they would be the first person to contact and should be able to help you. Any serious concerns regarding support or care packages should be address through the local authority social services duty desk.

### *Aim 2: A person-centred assessment is undertaken to agree the care and support package for your young person*

To enable a young person to move into adult services, an assessment of their needs will be undertaken. This assessment will consider the current services received through children's services, in many areas the eligibility criteria for adult health & social care will be different.

Depending on your young person's specific care and support needs, the assessment will either be undertaken by a social worker on behalf of the local social services department or a nurse assessor from the local Clinical Commissioning Group (CCG) who will be able to do the assessment for NHS Continuing Health Care.

The needs assessment should involve the family and any professionals involved with the young person and will look at all their needs, such as what support they need to undertake daily tasks, e.g. dressing; what support they may need throughout the day to undertake activities, this may be attending a day-centre or having a PA to support them to go out independently, where they would like to live, will they continue to live at home or move to residential or supported living. All these things will need to be considered and assessed. Any health needs should also be noted, such as epilepsy and if they are PEG fed, or if they have repeated bouts of ill health, particularly those requiring hospital admissions.

Once the assessment has taken place the social worker will write a care and support plan that would be agreed by the young person, their family, and professionals. Once agreed this package would be put forward to a social services panel for funding approval. They may agree the package in full or require some adjustments to be made.

If they feel there are significant health needs that require specialist health care involvement, they may undertake a Continuing Health Care Checklist (This may also be done at the initial assessment). If the checklist identifies significant health needs, they may then refer this to the local Clinical Commissioning Group to undertake a full NHS Continuing Health Care assessment, using a Decision Support Tool to assess and measure level of clinical need.

The NHS Continuing Health Care assessment will take a similar format to the social services assessment, with the young person's family and any professionals involved at the meeting. They will use the Decision Support Tool to help them gather the information for the assessment, this is broken down into 12 separate care domains, such as breathing, nutrition and food, and mobility. Information is recorded in this tool against each of the care domains, the level of need is then rated by their risk level such as low, moderate, high, or severe.

Once the assessment has been completed, the assessor will make their recommendation to the Clinical Commissioning Group panel, who will make the final decision. They will write to you and inform you of their decision and how they arrived at that decision.

If you are not happy with the decision made by either social services or the CCG then you have the right to appeal that decision. Information about how to appeal should be sent to you in writing, along with the written decision letter.

### *Aim 3: Services should be age appropriate and address the young person's needs in a person-centred manner*

Young people with Rett syndrome may have significant health needs and this can form a large part of their support. However, many would like to live like their peers, staying connected with friends, going to college or day activities, possibly living outside the family within either a supported living or residential setting. Their situation should not be just about their health needs.

### *Aim 4: Annual Review of the care & support package for your young person*

Once a care and support package has been agreed, this will be funded by the local authority adult social care department, where health needs are significantly high, then your young person may be eligible for Continuing Health Care, in which case funding would be through health, and in some instances the packages would be funded jointly. https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/.

Adult social services should look carefully at care plans and identify where any further information, training or support is needed for particular interventions.

An annual review should be a multi-disciplinary meeting, attended by professionals supporting and caring from the young person. This could include support staff and family, home managers, GP, health & social care professionals and therapists.

The meeting should look at how the young person's care and support needs are currently met, if there have been any challenges in meeting these, or if the needs have changed during the past year. If there have not been any changes then there will be no changes to the care plan, and it will be reviewed again in 12 months.

If there have been some significant changes in the young person's needs or there have been challenges in meeting those needs, it may mean that another full Care Assessment needs to be undertaken, in which case the local health & social care team would need to arrange for this to be done.

### *Aim 5: GPs and other primary health care professionals, develop a relationship with the young person and their families/carers*

Prior to adulthood a young person's health needs are usually overseen by a paediatrician, once that young person turns 18, the point of contact for all their health needs will transfer to their GP.

The young person's health may be stable at the time of transition, but the GP should be included in any full needs' assessments, so they have a good understanding of the young person's health needs at the time.

From the age of 14, ideally the GP should undertake an annual health check/review. This is a good opportunity for the GP to get to know your young person and to understand better the complexities of the condition.

The Rett Disorders Alliance has produced an extensive Health Checklist for clinicians and health & social care professionals. This can be downloaded from our website https://www.rettuk.org/resources/resources-for-families/rett-disorders-alliance-health-checklist/ if you would like a paper copy please contact us at the office.

### *Aim 6: A young person's complex health needs within secondary care setting are transferred to an appropriate lead clinician.*

When a young person has complex health needs, such as epilepsy, breathing irregularities or other ongoing needs, requiring regular monitoring or interventions by a lead clinician, it is essential that there is a lead named person to take over that care within the adult health provision and ideally there should be a suitable transition and joint reviews prior to the full transfer of care. You will need to be the instigator of this though as it is not something that is routinely offered. Ask your paediatric specialist to identify who will be taking the lead in adult services in that discipline, ask for a transition meeting so there is a comprehensive handover to that person.

If there have been regular admissions onto a children's ward and it is likely that these will continue once the young person reaches adulthood, it is important that the adult ward likely to oversee these admissions are aware of the young person and their specific needs, including how they communicate, their likes and dislikes.

Consideration should be given to the needs of young adults in terms of clinic arrangements – thinking about appropriate times of the day, the location and duration of appointments, communicating about appointments.

It may be helpful to produce a health passport for your young person, which provides important information that health professionals will need to know about your young person. A good example is the Rett UK Health Passport, which can be downloaded from the website, filled in and then printed. https://www.rettuk.org/resources/resources-for-families/health-passport/

### *Aim 7: Short break or respite needs of young people and their parents/carers are considered and provided in the most appropriate setting*

Short breaks for children are often provided by children's hospices and other voluntary and statutory agencies and these needs should be reviewed to ensure that short breaks for the young adult remain in the most appropriate setting.

If you have not used short break or respite services before, now your young person is moving into adulthood, it may be something you will start to think about. It can be a good idea to get the young person used to the idea of being supported by other people, either within their own home or in an external setting, and perhaps acquainting them with the idea of being supported and cared for outside the family home. Consideration should also be given about the future and think about what will happen in the long-term.

Short breaks should be provided by your local authority. They come in a variety of formats and can last from just a few hours to a few days, sometimes longer, depending on the type of provision and the needs of your young person and family.

Short breaks can mean that everyone in the family has a break, the young person may be supported outside of the home and make new relationships with support workers and make new friends. The family can do some of the things that they are less able to do when they have the young person with Rett syndrome with them.

Information about short breaks and respite care in your local area, can be found on your local authority website, under 'Local Offer.'  This should list all the places that may be able to provide services for your young person to access.

For additional information, you could also contact your local Carer's groups or visit one of the national carer's charity websites. https://www.carersuk.org or https://www.carerstrustcpn.org.

### *Aim 8: Parents are included as appropriate*

It is important to ensure that parents are included in caring for their young adult. Many young adults with Rett syndrome will still be dependent on their parents being involved in the decision-making process and often want their parents to be close to them at times when their health needs increase or when they must stay in hospital, especially if this is in unfamiliar adult critical care settings.

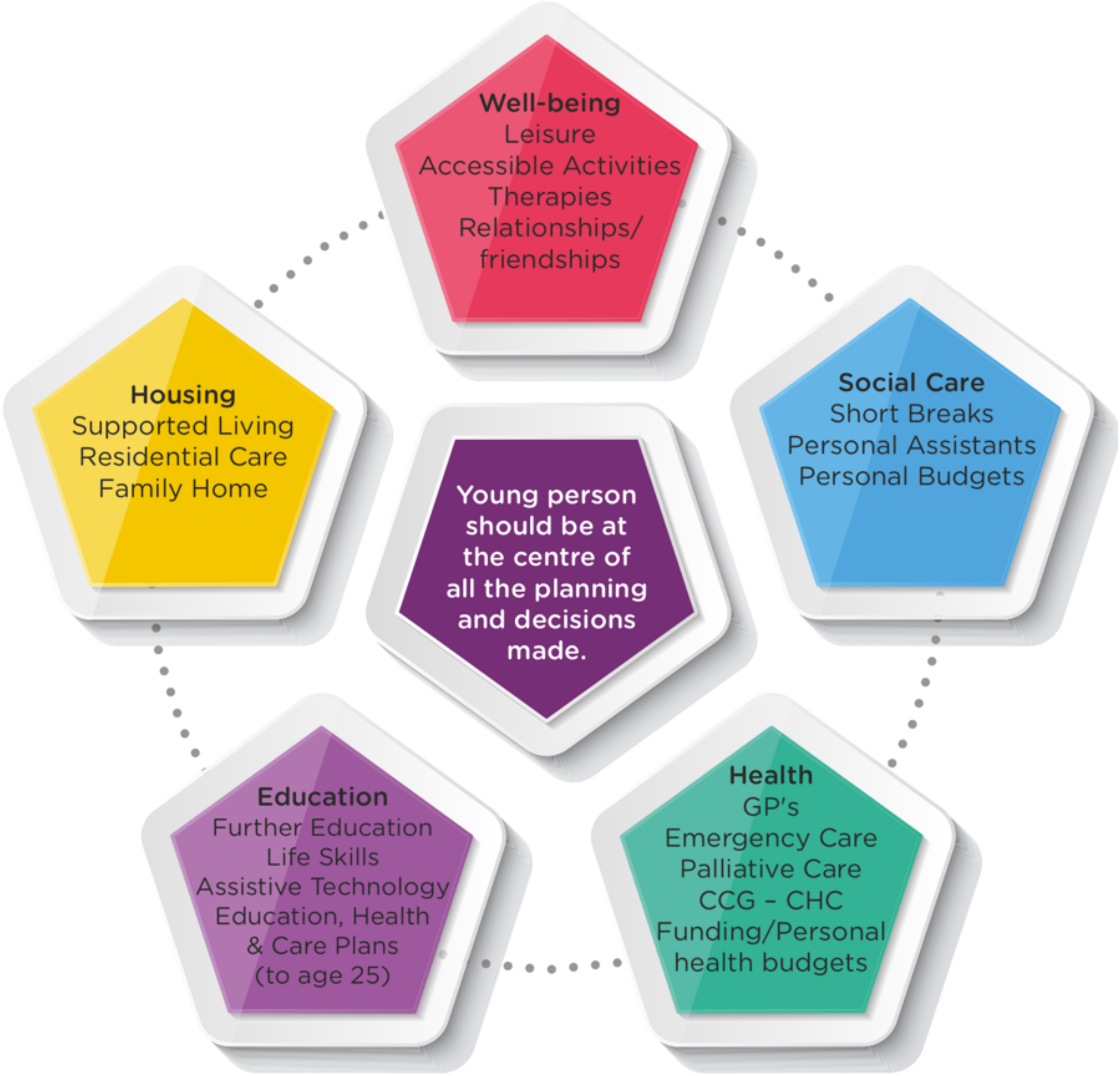
Many parents play an active caring role for their young adult children and have been experts in their care over many years. Whilst taking the lead from the young person, care should be taken to ensure that parents are listened to, and their views respected.

It is important to remember that as a parent to a young person who may lack capacity, any decision regarding, health & welfare or finance, could be subject to a Best Interest meeting decision, if you do not have Court of Protection Deputyship.
https://www.gov.uk/become-deputy

The roles of different agencies in adult services

There will be several different local authority departments and professionals, working together to make the transition a positive experience for the young person their families, some of the key people are identified below.

Remember, the young person should be always the central focus of transition.



## Links

Scotland - Co-ordinated Support Plan

Scotland - Factsheet on Co-ordinated Support Plans

Northern Ireland – Statement of Special Educational Needs

Wales – Individual Development Plan

NICE Transition from children to adults' services – Quality Standard

Preparing for Adulthood Funded by Department for Education (DfE), Provide expertise and support to local authorities and their partners to embed preparing for adulthood from the earliest years. Working to ensure that young people with SEND achieve paid employment, independent living, housing options, good health, friendships, relationships, and community inclusion.

Transition Information Network Sharing information and good practice for disabled young people, families & professionals

Help with supporting someone with Rett syndrome to communicate http://www.rettuk.org/resources/resources-for-families/communication/