Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/ Challenging Behaviour:

Technical Document -

Chapter 6.2 Appendix 2 – Summaries of Existing Guides

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Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/Challenging Behaviour - Chapter 6-2 Appendix 2: Summaries of Guides Pertaining to Professionals, Families and Young People with learning disabilities and mental health problems and their Families

Part 1. A summary of selected guides for professionals involved with families and individuals with learning disabilities and/or mental health problems

Department of Health (2006) *Transition: Getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services.* Department of Health, London.

Functions of the Guide

This good practice guidance was developed as a result of the National Service Framework for Children, Young people and Maternity Services vision for better transition planning between children's and adult's services. It focuses on highlighting current problems in transition planning for adolescents with significant health care problems. These individuals require continuing care as an adult and too often experience an abrupt transfer of care or even no official transfer at all.

This guide is aimed at health professionals, although acknowledges that transition is successful with a multidisciplinary input. It focuses on their lack of training and expertise as a significant inhibitor of successful transition planning. The suggestions and evidence of good practice that make up this guide stem from the opinions of well-experienced professionals from paediatric and adult services from all over the world.

Key Messages

A number of issues have been identified as important in improving transition planning for individuals with long-term conditions.

'Professional's Knowledge and Skills'

The guidance highlights that young people view professionals as possessing inadequate age appropriate communication and consultation skills, leading to professionals consulting parents instead of the young person, 'You get really fed up of other people making the decisions because it is your body and you want a say in it'.
These professionals also require a greater understanding of issues that affect all adolescents as well as those with long-term conditions, such as puberty, skin problems, and psychological and emotional difficulties. This guidance provides evidence of the successful use of several educational interventions that have increased general practitioners knowledge and awareness of some of these issues.

Finally the guidance emphasises the importance of teamwork between carers and professionals, and between health professionals and other individuals involved in the whole process of transition, particularly the Connexions personal advisor. The key to this partnership is adopting person-centred approaches in transition planning. The guidance highlights a study that found lack of person-centred planning to result in many young people not being placed in employment or education by the age of 19 (DfES 2003, cited in Department of Health, 2006).

A 'Good Transitions Service'

A number of measures have been identified with which to develop a good quality transitions service. A good transitions service should entail:

- Clinicians, managers and commissioners that have established relationships to ensure that an appropriate package of care is timely delivered.

- Paediatricians, adult physicians, and GP's that have acknowledged their 'differing perspectives' and have developed relationships to try and circumvent the culture clash of paediatric and adult oriented services.

- 'An agreed policy of timing of transfer'. The timing of official handover from children's and adult's services should be based on how well prepared the young person is, and not on their chronological age.

- Consideration of services users in service design and delivery, and in access to information from multi-agency settings.

- A 'preparation period' that aims to identify and develop the skills required for the individual to function as an adult user of services (i.e. skills of independence, making choices and decisions). This period also provides time to develop a schedule of the likely timing of official transfer of care, with the individual.

- Fail-safe mechanisms that ensure the young person attends appointments and is not lost during the process of transition.

- A dedicated transition team or transition co-ordinators within a team that have the sole responsibility of ensuring that all young people go through a transition process.

Implications for young people with learning disabilities and mental health problems going through transition

The recommendations that constitute this guidance are useful as it highlights some of the problems of transition planning for our subject of interest. The key messages from this guidance are adaptable to anybody that is involved in transition planning. For example, a key message from this guide is that transition planning should be managed as a process and not a single event. Therefore, those involved, namely managers, professionals and commissioners of services, should adopt this attitude in their working practice. It is recognised that this fundamental change in attitudes of professionals and managers can have a positive impact on the success of transition planning. This is also important when transition planning for young adults with learning disabilities and mental health problems and is recognised in the literature.

The recommendations of a good transitions service are useful in that they are not specific to health care transition for young adults. The emphasis of these recommendations focuses on the importance of an active partnership between professionals and managers, as well as between professionals, families and service users. Also highlighted is the importance of the young person developing skills that are appropriate for adulthood. The recommendation for a 'preparation period' can also be a useful technique that schools, families and the Connexions personal advisor can adopt when transition planning for young people with learning disabilities and mental health problems.

Department for Education and Skills (2005). *Including Me. Managing complex health needs in school and early years settings.* Council for Disabled Children, London.

Functions of the Guide
This comprehensive guidance document is aimed towards helping local authorities, early years settings provided by both local authority and voluntary agencies, and health professionals to develop policies that help children and young people with complex health care needs to access appropriate health and education. This guidance defines children with complex health care needs as those between the ages of 0 to 19 that may have 'restricted mobility and breathing, incontinence problems and those prone to infections'. It is these conditions that have excluded such children in accessing appropriate education and this guide aims to highlight the process of developing policies that ensure we adhere to the commitments outlined in the government green paper Every Child Matters.

Key Messages
The guidance is divided into a number of chapters that discuss the steps required to develop local authority policies:

Developing Joint Partnerships
This chapter provides examples of initiatives used across the country that have developed partnerships across agencies for the benefit of young people with complex health care needs. It is emphasised that developing local area policies must take into account statutory responsibilities as well as the resources available locally. A policy must be developed 'through joint working between education, health, social services and the voluntary sector'. It therefore must include all individuals representative of these organisations such as head teachers, school nurses, doctors and community paediatricians. Such an approach is crucial in identifying the responsibilities of each individual, and clarifying the tasks these individuals fulfil from the parents perspective.

Schools and Early Years Perspectives
This chapter emphasises the need for schools and early years settings to have policies in place for supporting their students with complex health care needs. This policy would help identify the 'roles and responsibilities of members of staff in supporting these children' and thus clarifies the responsibilities for parents. A policy would also help identify what the school expects from parents in terms of being kept informed of the child's changing health needs.

Risk Management and Assessment
It is important for risk management and assessment policies to be present when supporting young children with complex health care needs within schools and early

years settings. Many of these individuals are technology dependent thus requiring staff to be adequately trained in their use. There is an element of risk associated with the use of some of this equipment. Risk management policies will ensure the safety and well-being of both staff and the young person and would facilitate the young persons inclusion to the appropriate curriculum and health care both on-site and off-site school and early years premises.

Health care plans

All children within an early years and school setting should have a health care plan that sets out the specific health needs of the individual and the support they require. As a result, the health care plan should identify the duty of the staff and parents in supporting a particular aspect of health. A health care plan will also identify areas in which staff requires training in to be able to provide the relevant support.

Training of Staff

Supporting children with complex health care needs requires training in some specific health related equipment. Staff training must be included in any policy that discusses the support of children with complex health care needs. This chapter provides a number of examples from across the country of joint funding for multi-agency training.

Support Arrangements

Children with complex health care needs require support for their health as well as for their education. Examples are provided of many areas creating jointly funded posts that train staff in fulfilling the child’s health are as well as education needs.

(N.B. Throughout the document, examples are provided of the ways in which local areas have developed health action plans and risk management assessments etc, in order to be able to support their young children in early years or school settings.)

Implications for young people with learning disabilities and mental health problems going through transition

This guidance provides useful recommendations to support children and young people in accessing the curriculum. Of particular interest for our subject is the examples provided on developing joint partnerships, training of staff, health care plans and developing risk management and assessment protocols. Even though this document focuses on children and young people between the ages of 0-19, the benefits of developing appropriate local policies on transition planning for this group of individuals is not discussed.

The main focus of this document is to develop local policies that improve the support and access to education and healthcare for young adults that are ‘technology dependent’. Much of the guidance on staff training focuses on developing the skills required to use equipment within the school setting. Therefore, much of the focus of this document is not specific to individuals with learning disabilities and mental health problems. Nonetheless, this guidance highlights the steps required to develop local policies in helping to include disadvantaged young children and adults in gaining the most from the national curriculum.

Royal College of Nursing (2004) ***Adolescent Transition Care – guidance for nursing staff*****, London.**

Functions of the Guide

This guide is aimed specifically at facilitating the health care transition from children's to adult's health care services. Therefore it is oriented towards health care professionals such as nurses and paediatricians. The guide is divided into two stages firstly addressing the current issues and concerns when transition planning for young individuals. Secondly, it identifies the lack of a coherent framework for the transition process aims to amend this by providing a sample practical framework for working with young people going through transition. The guide focuses on the transition of young people aged between 10 and 20 with physical and medical conditions.

Key Messages

Stage 1: Key Issues in Transition Planning

The guide highlights potential concerns and problems for professionals, parents/carers and the adolescents with disabilities, which need to be addressed during the transition process. These include concerns of service user involvement in decisions concerning their own health care concerns for the family in 'letting go' of their child, and concerns for the professionals relating to multidisciplinary working and the 'attitudes of other professionals'.

It is suggested that these barriers prohibit seamless transition planning and may be reduced by a number of initiatives including:

- Encouraging young people to take the initiative in considering aspects of their health care, independently of any adult sources of support. This may involve exploring the possibility of having appointments with their doctor alone.

- Planning early allows ample time for professionals to collaborate with each other and with the families/ young person to set common plans of action.

- The young person should be involved when important decisions are being made as well as during the whole process where their opinions should be consistently sought.

- Professionals from paediatric and adult services should be involved in multi-disciplinary training events. This allows individuals from different professional backgrounds to share their knowledge and experience.

- Families should have access to a key worker. This individual will have established relationships with the family and young person and may facilitate a less stressful transfer of care.

Stage 2: 'Transition in Practice' using a checklist

Three stages of transition are defined: early stages (12-14 years), middle stages (14-15 years) and late stages (15-16 years). It is recommended that the professional (probably the nurse) possess a checklist for discussing aspects of a young persons health care transition, for each of the defined stages of transition. The aspects of health care highlighted in this document include 'self-advocacy', 'independent health care behaviour', 'sexual health', 'psychosocial support', 'educational and vocational planning' and 'health and lifestyle'.

The checklist provided highlights how breaking down discussions of a particular aspect of health care into 3 distinct sections addresses some of the barriers to successful transition planning, identified in the first section of the guide. These three sections include:

1. Identifying the behaviours to be addressed.
2. Identifying actions to address the behaviour.
3. Evidence of the young person addressing the behaviour.

Implications for young people with learning disabilities and mental health problems going through transition

For young people with learning disabilities and mental health problems effective transition in all aspects of life including health is vital. This documents main focus is on ways health professionals can help the young adult to develop self-advocacy skills in relation to health decisions. The planning checklist encourages professionals to begin familiarising the individual with the concept of choice in the early stages of transition (ages 12 to 14 years) so that by adulthood (between ages 16 to 19) the individual is accustomed to making their own decisions about a health condition. Other professionals who are involved in the transition of young adults from school to further education, future employment and independent housing can modify the planning checklist according to their requirements.

This guide serves as a useful tool for professionals working with young people to prepare for the challenges associated with adulthood.

Foundation for people with Learning Disabilities (2003). *Good Practice guidelines in supporting older family carers of people with learning disabilities*. Mental Health Foundation, London.

Functions of the Guide

An older family carer can be defined as any persons aged over 70 that care for a person with learning disabilities at home (Valuing People, 2001). This guide is oriented towards improving the care of older family carers by sharing good practice information. It is particularly dedicated to help Learning Disability Partnership Boards, commissioners and frontline workers reflect on the care they currently provide to older family carers and instigate improvements in local practice. Additionally, the guide is aimed towards the family carers themselves to inform them of government recommendations towards the support of older family carers and of the supports they should receive.

The guidelines have been produced as a result of a 3 year project led by the Foundation for people with learning disabilities, named the Older Family Carers Initiative (OFCI).

Five guidelines have been produced that can be used in conjunction with each other.

Key Messages

Guideline 1 summarises the aims of the project and outlines the key messages from old family carers and people with learning disabilities regarding their support. Also outlined are the requirements set in Valuing People to ensure older family carers and their relatives with learning disabilities are supported. Valuing people stipulates that local authorities and partnership boards need to have mechanisms in place that identifies older family carers in advance, particularly carers that continue to live with their relatives who have a learning disability. It is crucial that services are planned in partnership with family carers and their relatives using person centred approaches. These recommendations are discussed separately in guidelines 2-5 of the remainder of this guide.

Guideline 2 provides information of ways to identify older family carers in order to understand their support requirements and hence improve the support services they receive. It is recommended that before Learning Disability Partnership Boards begin to collect information on older family carers, commissioners and managers consider how they are going to gather the information and what they will do with that information once it has been collated. Whereas family carers of relatives that are currently in receipt of services can be easily identifiable, it is recognised that 'hidden families' of individuals that previously have not used services require creative consideration and thought in order to be identified by local authorities (e.g. through GPs and voluntary agencies). It is suggested that the information on young peoples and family carers collated during the transition from children's to adult services be retained and used effectively for identifying older family carers, and when their support requirements may differ.

Guideline 3 discusses the confidentiality concerns and responsibilities for recording information on older family carers. Learning Disability Partnership Boards have been assigned the responsibility to oversee the implementation of Valuing people and hence recording information on older family carers. Policies on information sharing also need to exist, so that families are not suspicious of sharing details with organisations. Family carers may also benefit from having regular contact with workers responsible for information collecting and sharing. Secondly, this guideline identifies the types of information that should be recorded about the older family carer and their relative, though this is very much dependent on the commissioners' and managers' decision as to the uses of the information needed to be obtained. The information requirements include 'personal care needs, social and health needs, accommodation, transport, communication needs, support required for daily living tasks, and the level of support that is required'. Finally, it is recommended that workers collecting this information do so through personal home visits, which allows them to explain the need to collect such detailed information and also to reassure the family carer.

Guideline 4 discusses the uses of a carers' needs assessment and the approaches that should be taken when assessing an older family carer. For example, 'people carrying out assessments must bear in mind that going through an assessment process may feel both threatening and negative to older family carers'. It is therefore appropriate for a worker familiar to the family to carry out a carers' needs assessment as well as the carers having the opportunity of somebody trusted to be present at the meeting. The remainder of this guide is aimed towards the individuals carrying out the carers' needs assessment. Its advice includes the need for the assessor to be empathetic towards the family carer and to approach the assessment in a holistic person-centred way. A checklist of areas to cover is provided at the back of this document.

Finally, guideline 5 discusses ways of involving any family carer representative including those that are older in consultation and planning meetings of services that affect their experience of caring. In order to achieve an adequate representation of family carers in partnership board meetings, it is suggested that partnership boards be flexible in the number of representatives that are able to attend. Carers that are not able to attend should be allowed to make known their views via other methods such as e-mail, fax or telephone. This is particularly important for carers that have mobility problems or other barriers to attending meetings. Other ways of overcoming practical barriers in the involvement of older family carers include taking into account the timing and location of meetings, paying family members to attend as well as producing documents that are accessible and easy to read. Finally, it is important that family carers are supported in their role in partnership board meetings. This can be achieved through an induction pack, which explains their roles as well as providing link workers who ensure family carers are prepared and actively involved in partnership board meetings. Partnership boards can also do much to support family carer representatives through involving these carers as much as possible as well as actively informing carers of developments in an accessible manner.

Implications for families of young people with learning disabilities and mental health problems at transition

Though the number of older family carers that are 70 or over that support a young person with learning disabilities and mental health problems between the ages of 14-25 is unknown, this guide may be of particular use to families of individuals at the higher end of the age range that is of our interest.

There are many aspects of the guide that are applicable to family carers of any age. Many of the views of older family carers of people with learning disabilities also reflect those of family carers of young adults with learning disabilities and mental health problems. Guideline 1 highlights that older family carers want:

- ‘To feel confident that the organisations which are likely to be involved in their relatives care in the future know of both their existence and their needs’.
- ‘Information about the support available to enable them to continue their caring role and to plan for the future when the time is right for them and their relative’.
- ‘Flexible breaks from caring…and opportunities to build positive relationships with individuals and services likely to have a role in supporting their relative in the future’.

Much of these needs are also reflected in the literature on family carers of people with additional mental health problems. Therefore much of the advice on carers’ assessments (Guideline 4) and involving family carers (Guideline 5) is particularly useful. These sections discuss the right of any carer to an assessment of their needs as well as their involvement in deciding the services they require, based on their assessed need. It is important for family carers of any age to understand these rights as well as family carers of individuals with learning disabilities and mental health problems going through transition to be aware that these assessments should cover all aspects of the carer's life and not just their role as a carer.

The involvement of family carers and service users in decisions of the types of services they require in the future should feature highly in transition planning meetings. Though this guide discusses the involvement of family carers in decisions of their own as well as their son/daughters support services post-transition, it is useful for families to be aware that they should be involved in decisions regarding their own as well as their relatives support needs and that sufficient support must be provided to ensure carers and service users are able to convey their wishes and aspirations.

As this guide is additionally aimed towards Learning Disability Partnership Board members, commissioners and frontline staff working with the individuals as well as their families, the suggestions for family carer identification and involvement can also be applied for family carers of any age with learning disabilities and mental health problems. This group of individuals may also be 'hidden' to services and much work id required to identify them, understand their needs through involvement in partnership board meetings and to provision services adequately according to the needs identified.

Foundation for People with Learning Disabilities (2005). *Linking Up. Emotional support for young people with learning disabilities.* Mental Health Foundation, London.

Functions of the Guide

This guide was published as a follow up of the *Count us in* enquiry as well as the *Mind the Gap* project. It aims to aid particularly Connexions personal advisors across the UK to achieve some of their responsibilities towards individuals with learning disabilities and additional mental health needs at transition.

The Mind the gap project highlighted some of the work of the Connexions service in Somerset and as a result, instigated further research of the 'Somerset model of transition planning'. The findings from interviews with connexions staff, other service providers and commissioners form the basis of this guide.

Key Messages

The main messages of this guide inform Connexions staff of the relevant policy stating their duty towards children with learning disabilities in transition planning. In addition, information regarding the emotional needs of people with learning disabilities and ways to identify and alleviate some mental health symptoms is included. Evidence of good practice is provided through stating some of the duties of the transitions personal advisors from Somerset. These main messages include:

Policy on supporting young people with learning disabilities

- Valuing people states the Connexions personal advisors must attend the first transition plan meeting in year 9.
- They can work with that individual up until they are 25.
- Connexions personal advisors have a duty to oversee all aspects of the young person's transition plan.

Identifying mental health needs:

- Connexions personal advisors have a duty to take into account the emotional needs of individuals with learning disabilities.
- The study into Somerset Connexions found that almost all young people with learning disabilities experienced heightened aggression, anxiety or obsessive behaviours during transition.
- It is important that the Connexions personal advisor get to know the young person. The young person may feel more confident to open up to someone they trust.
- Getting to know the young person also places the Connexions personal advisor in a better position to monitor changes in mood or behaviour.

Alleviating mental health problems

- Understand the source of the young person's distress. This can only be achieved by really getting to know them.
- Encourage and support the young person in activities that enrich their life.
- Develop links with mental health professionals and services. Encourage joint meetings and training programmes.
- Support the young person to visit their GP concerning their emotional well-being.
- Connexions PAs can ensure the young person receive a person centred transition plan, thus allowing the young person more control over their future.
- Encourage young people to support each other, thus allowing them to maintain/form friendships and nurturing self-confidence.

The Somerset Model

- Somerset has appointed four full-time Transitions personal advisors that are focused on the transition of young people with learning disabilities.
- These workers are partly based with the Somerset connexions services as well as the adult community learning disability team.
- Having these individuals based within a multidisciplinary team allows them to exchange ideas with other professionals and share ideas of good practice.

Other messages

- Connexions personal advisors can map services in their local area allowing them to identify which referrals have benefited young people.
- Mapping allows Connexions personal advisors to identify the right support for individuals and share information with other colleagues.

Implications for families of young people with learning disabilities and mental health problems at transition

This guide appears very important for Connexions staff to work towards preventing the rise in emotional distress during the transition process. It contains a vast amount of information on the nature of mental health distress for people with learning disabilities. The work from Somerset highlights the achievements of joint working on families and individuals and provides a useful model for other Connexions services across the UK.

Given the ideal position with which Connexions personal advisors are placed to detect mental health problems, much of the advice equips workers with knowledge of where to go for an appropriate assessment as well as the types of support that may be required.

A guide such as this is ideal for connexions staff to refer to should they suspect emotional distress in any of their young people.

Part 2: A summary of selected guides for families of individuals with learning disabilities and/or mental health problems

Foundation for people with learning disabilities (1998). *Learning disabilities and the family: The teenager with a severe learning disability*. The Mental Health Foundation, London.

Functions of the Guide

This guide is intended for parents, family members and friends of teenagers with severe learning disabilities. Particularly for parents, the guide describes and informs of the process of transition, with the aim of making the process less daunting for parents.

The needs of young people, who at this stage are making a variety of physical and emotional transitions, are also addressed with some suggestions being proposed.

People with a learning disability, their parents, friends and professionals, have informed the guide and therefore the recommendations made are pertinent to these groups of individuals. A list of national organisations is provided at the back of this document as well as the addresses and contacts of local sources of information for these individuals.

Key Messages

Fulfilling the lives of young adults with severe learning disabilities

Parents stated it was important that future provisions made for their child made the most of their strengths. It is hoped that by explaining the process of transition and by stressing important events that should occur, parents and the young person will be able to make a more informed decision regarding suitable future provisions. A number of key facts about the transition process are stated:

- Parents should know in advance of the upcoming transition plan in the year their child turns 14.
- Parents and families should then get together with the individual to prepare for the transition plan. This allows time to get an idea of what is important to the individual.
- It is suggested that parents work with the child to indentify what is important to them at each stage of transition.
- Once an idea of the child's future needs are ascertained, the guide also suggests that parents explore local services for young adults via a community care plan provided by the local authority.
- A checklist of questions is provided to remind parents of areas to look into.

'Looking at the range of needs and considering various options'

Parents informing the guide identified that it was not the lack of appropriate post-school provision that posed significant barriers for their child at transition, but the deficit in range of activities available for their child. This guide provides a list of opportunities available to children with severe learning disabilities after leaving school, with their contact details for parents to explore. These include:

- Continuing further education. It is suggested that families contact local further education colleges for a prospectus or to speak to the tutor in charge of special needs.
- Going to work or gaining work experience.
- Exploring a range of social, leisure and community activities. It is suggested that parents seek advice from a social worker that may be present at the transition meeting. If they are not, the parents can invite them or contact their local social services department.
- Living away from home. Parents are provided with a list local housing arrangements should their child wish to move out of home.
- Other suggestions: It is important for families to explore different opportunities before making a definitive answer. For example, if a family is making a decision on which day centre is suitable for their child, it is suggested that they visit it or speak to other people who attend the day centre. It is equally important for carers to ensure they receive a carer's assessment to ensure their needs are also met.

'Addressing immediate concerns'

As well as securing the future provision of their child, it is also important to address the immediate needs of the individual. Parents are concerned that as their child gets older they will enjoy fewer social opportunities outside of home. A number of suggestions are made to prevent this from occurring:

- Explore college/school voluntary schemes.
- Ask social worker about local activities, clubs and befriending schemes.
- Assist the child in forming a circle of friends or a circle of support.

'Everything seems so expensive as they get older'

Another common concern expressed by parents or carers of individuals with severe learning disabilities was the high costs associated with their care. This guide suggests that families contact the social security office, or the Citizens advice bureau as well as speaking to a social worker. This will assess the eligibility of the individual to extra benefits. Carers can similarly obtain benefits dependent on their annual salary.

Other recommendations

Often there is a tendency for carers to avoid addressing sexual development in individuals with learning disabilities. Parents are advised to check with schools and colleges to ensure they are receiving the appropriate sex education.

Finally, it is important that all individuals involved in the transition process are aware of and familiar with how the individual communicates, so that appropriate arrangements can be made.

Implications for families of young people with learning disabilities and mental health problems going through transition

This guide appears significant for parents of individuals with learning disabilities and mental health problems. Although ways of addressing mental health problems during transition are not discussed explicitly within this document, many of the suggestions nevertheless promote emotional well being in young adults with learning disabilities. For example, the guide encourages parents to explore the immediate and future needs of their child. Some of the suggestions made, such as encouraging the set up of befriending schemes or exploring daytime social activities with the social worker, may also prevent the escalation of emotional ill health in the young person during the transition process.

The guide is oriented specifically towards informing parents of their rights and entitlements during transition as well as providing additional suggestions of ways to ensure their child benefits from the process. As much of the literature on family's experiences suggests that families and the young person feel under informed of the transition process and of their entitlements, this guide focuses on resolving these concerns through informing families. The information provided explores a range of needs, assessments and opportunities that parents can explore allowing a variety of local provisions to be researched. The recommendations are applicable to many young adults with a range of disabilities and, therefore, allow parents of children with learning disabilities and mental health problems to use this document as a useful source of information when embarking upon the transition of their child to adult oriented services.

MENCAP (2002). *What next? A guide for the parents and carers of young people getting ready to leave school.* MENCAP, Belfast.

Functions of the Guide

This guide is particularly for parents and carers of children with statements of special educational needs. It stresses the legal and obligatory roles of the school and social services on the transition process as well as the roles of other agencies. In addition, the family and young person are provided with advice for effectively preparing for transition meetings.

The chronological stages of the transition process (beginning at 14 and extending to 16 or 19) are presented and advice is provided for each of these stages. The guide aims to outline the stages of transition so that families are aware of what to expect and subsequently are better prepared for the process.

Key Messages

The most important messages the guide aims to communicate can be grouped within three important stages identified in the transition process:

- 'Preparing for the transition planning meeting'
- Annual Review of the Transition Plan.
- Preparing to leave school.

<u>'Preparing for the Transition Planning meeting</u>

A number of useful suggestions are provided for parents to consider before their first transition planning meeting:

- Discuss with the young person, their aspirations for the future.
- Collect together some questions to ask during the transition meeting.

- Be aware of who is attending the meeting. If there are individuals who have experience with the young person and have not been invited, parents can request the school to invite them.
- On the day, it is important that the young adult's views are sought after and that there are opportunities for the individual to make a valid contribution. Families/carers should ensure that this occurs.
- It is also important for families to have a clear understanding of the conclusions and action points resulting from the meeting.

Annual Review of the Transition Plan

The 'social, academic and developmental needs' identified at the first transition plan should be reviewed yearly until appropriate post-school provisions are made. The transition plan should consider a number of post-school options includin transfers to other schools, Further Education College, vocational training, employment services and day services, though this is dependent on the individual and what they desire for their future.

The guide highlights the responsibility of the young person's school particularly at this stage, in assisting the young adult to move to any of the considered options. Although this is a guide for families and carers, this section highlights how schools should promote awareness of the range of post-school activities. It is, however, useful for parents to be aware of the duty of schools to regard a range of possible options.

Preparing for adulthood

For many individuals with learning disabilities, new environments are often the source of much stress. This guide highlights some important steps families can take to ensure their son or daughter is prepared for the future. These include:

- Discussing any sources of anxiety with the young person.
- Making sure they are aware of what is going to happen and that they are familiar with the new environment. This can be achieved by arranging visits with the school, college or day centre.
- Encourage the young adult to be independent and make his or her own decisions.

Implications for families of young people with learning disabilities and mental health problems going through transition

This guide possesses great benefits for families of children with learning disabilities and additional mental health problems. The focus is on children with statements of special educational needs and therefore is particularly pertinent to our subject of interest. It outlines in detail the specific stages of the transition process, with advice for families of relevant parties that have key roles to play in the transition of many young adults to adulthood. Although not specific to individuals with learning disabilities and mental health problems, much of the advice offered to families covers practical methods of preparation for transition meetings and considering post-school options.

As well as signposting a variety of professionals for families to consider in the transition process, the guide encourages families to independently pursue future possibilities for their child by providing a list of contact details for various agencies Although, the guide appoints a considerable amount of responsibility towards the school in helping the young person enter adulthood, it also emphasises the importance for families to be aware of the variety of options, some of which the school may not have considered, and ways they can support their young child. As the literature has highlighted on many occasions the frustrations of families, particularly parents, at being unaware of their role in the transition process, this guide attempts to clarify the roles of families and the school in the different stages of the transition process.

For parents of young adults with learning disabilities and mental health problems, it is equally important to be aware of their roles as well as the obligations of other agencies in the transition process. These particular families will need to consider support for their child's mental health problem and consider the involvement of a health professional that has experience with learning disabilities. Additionally these families may require information for a wider range of post-school options as many of the options considered here may not be appropriate for their young person.

SEN Regional Partnership (Date unknown). *Thinking about the future? A parent's guide to transition planning*

Functions of the Guide

This guide is intended for parents whose child is entering year 9 and is about to begin the formal process of transition. Although, it is aimed at the parents of children who have support through School Action or School Action Plus and those with statements of special educational needs, this guide is also relevant for parents whose children are not statemented or do not receive extra learning support. The guide presents some of the common questions parents may have in mind when embarking upon the first formal transition process.

Key Messages

Initially, the guide sets out to describe the first transition meeting, as well as explain how parents can prepare and help their son or daughter prepare for the meetings. The key points for parents to consider when preparing for this stage of the process includes:

- Discussing with the child their future aspirations.
- Writing down any questions that have arisen from these discussions. In particular it is suggested that parents consider areas in which their child may require support, such as 'therapy or health care, transport, travel training and getting a place in college or finding a job'.
- Thinking about their child's strengths and weaknesses and noting down their own aspirations for their child.
- Asking the school or Connexions personal advisor to assist with preparing the child for the meeting.
- Finally, it is important that the school have invited all who must attend. The guide particularly highlights the responsibility for the school to invite the Connexions personal advisor. Parents must ensure that these individuals are attending. If they are not parents should receive a written statement from them prior to the first meeting.

Box 1 indicates the main features of the eventual transition plan, as described by the guide. This is useful for parents to know in advance so they are aware of what the transition meeting should cover.

Box 1. 'The Transition Plan should describe:

What your son or daughter wants to achieve.
How everybody who works with them will support them.
New skills they need to learn for them to achieve their goal.
How they will find out about their choices and who will help them do this'.

The guide introduces and prepares families for the multitude of assessments that they may receive as their child makes the transition from children to adults services. These assessments, such as the section 140 assessment and social services assessment, are described in terms of who will carry them out and their relevance for some families.

Finally, the guide provides a number of useful tips for parents when their child is approaching the end of school and preparing for the future. As the child and their parents lose the support from school, they may wonder whom to turn to for support as an adult. This guide highlights the usefulness of the Connexions personal advisor, the social worker and other voluntary support organisations for parents and young adults requiring support and advice following the transition process.

Implications for families of young people with learning disabilities and mental health problems going through transition

This guide's main objectives and messages appear similar to 'What Next?' There is a strong emphasis on preparing parents for the first transition planning meeting which should take place in Year 9. The guide presents some of the common questions parents may have in mind when embarking on the first transition meeting. The questions and subsequent comments are quite general and therefore families of children with learning disabilities and mental health problem may require answers to more specific questions that are more relevant to their child's presenting needs. Nonetheless, the comments are relevant to all families that go through a formal transition process with their young adult.

This guide highlights the names of some key organisations that are not mentioned in the 'What Next?' guide. It is mainly the duty of the Connexions Personal Advisor and social worker that is emphasised as crucial during the transition process as well as for the future. It is likely that the families and children with severe learning disabilities and additional mental health problems require longer periods to adjust to adulthood and therefore they will require continued support. Therefore, it is important for families of children with learning disabilities and mental health problems to be aware of these key messages from the guide.

Watson, D., Lewis, M., Townsley, R., Abbott, D., & Cowen, A. (2004) *All Together Better: A guide for families of a disabled child with complex needs,* Norah Fry Research centre, Bristol.

Functions of the Guide

This useful guide informs parents of individuals with complex health care needs who inevitably require support from a range of services and agencies. The guide acknowledges that many aspects of family life are not given enough attention by these different agencies and services. It aims to inform families of the types of support that can be gained to aid in all aspects of family life. The information that makes up the guide is taken from interviews with families of children with complex health care needs as part of the Working Together research project. Therefore, the suggestions made are valid and relevant to a range of families with individuals with complex health care needs.

Key Messages

The guide is separated into 8 sections that cover areas in which families may require extra support. This includes:

1. Getting the best from services and professionals.
2. Daily family life.
3. Accessible living
4. Family Finances: Financial well-being
5. An Ordinary life? Social well-being
6. Feeling good? Emotional well-being
7. Skills, learning and work
8. Standing up for your child’s rights

A final section provides addresses and contact details of a variety of useful organisations that offer additional support and confidential advice.

Each section communicates useful messages for families should they require extra support.

1. <u>‘Getting the best from services’</u>

Most of the families that this guide is aimed towards have encountered different professionals and services. The families that have informed this guide identify that ‘their contact with services and professionals is one of their biggest problems’. Although each family’s experiences with professionals are different, many families have found it difficult to meet large numbers of professionals and have large numbers of different reviews and assessments.

It is suggested that a key worker may benefit families experiencing such problems. The aim of a key worker is to establish close networks with the family and the individual. This provides them with an understanding of what support each member of the family needs thus allowing them to co-ordinate services accordingly and prevent families from receiving repeated assessments.

The checklist of questions provides a useful reminder for families to ask a member of the multi-agency service about the benefits of a key worker for their family.

2. <u>‘Daily family life’</u>

This section provides information about some aspects of daily family life where families may require assistance. In particular, handling a child’s difficulties with sleeping, mealtimes and transport arrangements as well as assistance with household chores for the family are discussed. The guide emphasises that families cover any problems experienced in daily family life, in their care plan as well as discussing aspects of daily life with GP's, community nurses, key workers or occupational therapists.

Of particular importance is the advice surrounding transport provision for children with special educational needs (SEN). This guide states that 'local education authorities (LEA's) have no duty to provide free transport for people with a SEN, and that each case is considered individually.' The guide also emphasises the importance of the role of the GP, health visitor, occupational therapist and community nurse in providing useful advice and support when considering the child's health needs. Both points appear to be of direct relevance for families looking after children with a statemented learning difficulty who experience additional mental health problems.

The checklist again provides a list of useful questions to be thinking about when preparing for a meeting with a key worker or other professional.

3. 'Accessible Living'

For families that require adaptations to be made in their home, seeking the advice of occupational therapists and key workers is recommended.

4. 'Family finances: Financial well-being'

For information about disability benefits or eligibility to benefits when a member of the family is going to work, the key worker or social worker can provide basic information. The Citizens advice bureau or Family Fund can provide detailed advice and information regarding the process of gaining disability benefits.

The checklist provides a useful number of questions for families to ensure that they receive everything that they are entitled to.

5. 'An ordinary life? Social well-being'

It is important for every family of children with complex needs to be able to discuss their needs as well as the needs of their child. It may be that families want to consider short breaks or respite so that they have the opportunity to rest and so their child has the opportunity to meet new people. This guide provides comprehensive advice and information for families regarding short breaks, respite, preparing to go on holiday and arranging for mainstream play provision for their child.

6. 'Feeling Good: Emotional well-being'

There are many sources of stress and pressure for all members of the family when caring for an individual with complex health care needs.

The guide provides a useful checklist of questions for parents to enquire about emotional support for themselves, their disabled child and for any other siblings.

7. Skills, learning and work

Access to appropriate educational provision is every child's right. The guide provides a variety of websites, and information of published fact sheets and documents to help parents get the appropriate educational support for their child.

It is also important for families to access learning opportunities including employment and training. These needs must be stated in a carer's assessment. The guide provides as list of useful websites that provide information about flexible working arrangements for families that take into account their caring responsibilities

8. Standing up for your child's rights

Finally, this section covers the 'importance of the child being able to communicate their feelings needs and wishes in their chosen way'. Although family carers possess invaluable knowledge and experience of their child, the emphasis is on the child being able to build close relationships with professionals and communicate their own needs and avenues of support.

It is suggested that building a close relationship with the key worker allows the child to become more involved with aspects of their own care. The names of other organisations, which promote young people to form positive relationships with professionals and encourage the involvement of young people in making decisions for the future are provided.

Implications for families of young people with learning disabilities and mental health problems going through transition

This guide is useful for families of young adults with learning disabilities and mental health problems. There is ample practical advice regarding everyday life problems facing families with disabled individuals.

Of particular interest for our subject is the section regarding emotional well-being. This section of the guide covers the experience of emotional ill health from the perspective of all family members including the disabled person, their parents and their siblings. The checklists of questions encourage families to enquire of professional sources of support and local support groups to promote emotional well-being and are subsequently relevant for all members of the family.

Although the guide is not aimed specifically at parents whose children are transitioning to adulthood, many of the topics that are discussed are relevant for parents to enquire during the transition process. Topics such as the possibilities of a key worker, sleeping problems or post-school work arrangements are all important aspects to cover in a young adults transition plan.

Royal College of Psychiatrists (2004). *A Checklist for carers of people with mental health problems: Working in partnership with psychiatrists and carers*, RCP.

Functions of the Guide

This document provides carers of individuals of any age with mental health problems a checklist of questions for psychiatrists. It aims to provide a means for carers to access all the information they require in order to care for an individual with a mental illness. Whilst this duty traditionally falls on the psychiatrist, it is acknowledged that many of these professionals fall short in fulfilling carers' information needs. This checklist aims to encourage a more interactive partnership between psychiatrists and carers of disadvantaged individuals.

Key Messages

The checklist serves as a useful framework for carers preparing for a meeting with a psychiatrist. The questions guide carers to discuss all aspects of the individual's care as well as their own care with the psychiatrist. Carers are encouraged to ask about the illness with which their relative has been associated with, the assessment, and the reasons behind any chosen methods of treatment. Similarly, carers are also encouraged to ask about sources of support for themselves and how these may be assessed.

This document places an emphasis on encouraging carers to become more proactive instead of passive recipients of professional advice, in order to gain knowledge of the best methods of care for the person they care for.

Implications for families of young people with learning disabilities and mental health problems going through transition

This guide encourages carers of individual with mental illness to enquire about diagnosis and treatment of the person they are caring for as many professionals fail to provide carers with adequate information. Similarly, many carers of individuals with learning disabilities and mental health problems also find that their information needs are unmet. Therefore, they may also benefit from a document that allows them to explore all angles of the individuals as well as their own care.

Adapting this checklist so that carers of individuals with learning disabilities and mental health problems develop their own criteria may be useful when preparing for meetings with professionals. Adopting this style may similarly benefit carers preparing for transition meetings, when meeting a range of professionals or discussing post-school arrangements with a key worker.

The flexibility of the checklist provided in this document allows its key messages to be incorporated by carers of a range of disadvantaged individuals and used with professionals from a variety of service cultures.

Foundation for People with Learning Disabilities (2001). *Meeting emotional needs of young people with learning disabilities. A booklet for parents and carers.* The Mental Health Foundation, London

Functions of the Guide

Intended for parents or relatives of young people with learning disabilities, this guide aims to equip families with knowledge of the prevalence of emotional difficulties in their young adults and provide examples of possible solutions to these problems. The guide particularly focuses on families of adolescents between 14 and 25 years old and the positive influence of families on fostering emotional well being.

The guide is also useful for friends, teachers and support workers of the young adult that are looking for ways to help the young person through adolescence.

Key Messages

The remainder of the guide is separated into two sections. The first covers practical strategies for families to promote emotional well-being, and the second highlights the types of support available for young people who experience mental health problems during adolescence. The key messages from these two sections include:

Section 1: 'Promoting Emotional Well-Being
A young persons sense of well-being may be helped by:

- Allowing the young person the chance to communicate effectively with others by having a range of friends whom they trust with whom they and can share their problems. It is important that families encourage the young person to stay in touch with friends through e-mail, text messaging, making phone calls and sending letters. Similarly teachers in school can also promote the young persons social well-being by encouraging other children to be involved with the young person and by arranging after school social activities for all children to participate.
- Promoting their confidence through having a circle of friends, belonging to a self-advocacy group, and allowing the individual to make their own choices in their life.
- Increasing their independency. This may result from being involved in community activities including social activities and voluntary work.

Section 2: 'Support and help for young people who experience mental health difficulties'
This section covers some possible causes of mental health problems in young people and equips families with ways of recognising symptoms as quickly as possible. The most important changes in behaviour that families should look for include the young person being more withdrawn, restless, tense, or irritable. There are more obvious behavioural changes such as disturbances in appetite and sleep that may also be symptomatic of mental health difficulties.

The final part of the guide informs parents of sources of practical and professional help for their own emotional and physical well-being as well as their young persons.

Implications for families of young people with learning disabilities and mental health problems going through transition
Much of this document is relevant to families of young people with learning disabilities and mental health problems. It addresses directly the impact of the young persons environment on mental ill health and provides a variety of possible solutions to the arising needs. It may be of particular relevance for families to have in mind ways of dealing with the young persons mental health needs, in order to seek advice from other health professionals during the transition process. This document is not specifically for families going through the transition process, but rather addresses mental health problems in young adults.

Although this guide is aimed at families or carers of young adults of a transitional age (between 14 and 25), the guide is equally valuable for family's pre and post transition to refer to for its advice and information about the emotional needs of their son or daughter.

Part 3. A summary of selected guides and information sheets for services users either learning disabilities and/or mental health problems

Foundation for people with learning disabilities (2003). ***All about feeling down: A booklet for young people with learning disabilities.*** **The Mental Health foundation, London.**

Functions of the Guide
In this context the term 'feeling down' refers to the emotional changes experienced by a young child during adolescence. The guide aims to educate young children with learning disabilities aged 14 to 25 about the experience of feeling down and provides a range of ideas to explore to promote emotional well-being.

Key Messages
The key messages from this guide can be categorised in four broad areas. These include:

1. Changes associated with growing up.
2. 'What's it like to feel down?'
3. Ways of feeling better.
4. Tips to 'keep on feeling good'.

1. Changes associated with growing up

This guide begins by introducing the physical and emotional changes that an adolescent experiences. The key message for individuals with learning disabilities is to be aware of these changes and to understand that these changes can be associated with happiness and sadness.

2. 'What's it like to feel down?'

This section covers the different meanings associated with 'feeling down' and explains how 'feeling down' can be manifested in different ways. Individuals are provided with descriptions of the different emotions associated with feeling down, such as being 'sad, angry, and upset'.

3. Ways of feeling better

A number of strategies are suggested to inform individuals of what to do when they experiences symptoms of low mood. These include 'being good to yourself' by participating in enjoyable events, purchasing rewarding items or doing some exercise. Other suggestions include talking to a family member, friend, key worker, social worker or GP about some of the feelings that are experienced.

4. Tips to 'keep on feeling good'

This section includes 10 tips for individuals to maintain feelings of well-being and happiness. The emphasis is on keeping socially active and meeting with friends regularly, keeping physically active and healthy by regularly exercising and on encouraging individuals to discuss their worries with other individuals.

Foundation for people with learning disabilities (2004). ***What is important to you? A booklet for people with learning disabilities*****. The Mental Health Foundation, London.**

Functions of the Guide
This document discusses aspects of life that individuals with learning disabilities have expressed as important to them, such as friendships, families and spirituality. Examples are provided of what individuals can do to improve these aspects of daily life, and consequently reduce many social barriers to inclusion.

Key Messages
Aspects of life such as 'friendships', 'family', 'getting together', 'finding time for yourself', 'spirituality' and ways of exploring a range of activities are discussed in detail within this guide. Individuals are provided with examples of what they can do in order to improve these aspects of their life. These key messages are:

- Get together with friends regularly or join a youth club to meet new friends.
- Have someone to talk to for advice and support. This may be a key worker, family member or God.
- Allocate a quiet space to relax. Having some calming pictures on the wall may also be beneficial.
- Express your feelings through other means such as drawing, painting a picture, playing music, writing songs or writing stories.

Scholl. C., & Dancyger, F. (2005) ***The Big Picture: Your Guide to Transition for young people aged 13 to 25.*** **Transitions Pathway Project.**

Functions of the Guide
This guide informs young people aged 13 to 25 with a range of disabilities of the process of transition planning. This document focuses on empowering the individual by providing them with detailed information regarding the transition process. The different stages of transition are highlighted and in-depth information for the individual at each of these stages is provided.

Key Messages
Initially, the guide describes the professionals that should be involved in the transition process such as a Connexions Personal Advisor (PA), the family, an advocate and the school.

The separate stages of transition identified and their relevant messages include:

1. 'Getting Ready, Years 8-9'

The young person should be aware of the individuals that are likely to be involved in the first meeting and would benefit from having their contact details at this stage of the process. Lists of areas that must be covered in the transition plan are provided for individuals to consider and discuss with other sources of support. These areas include 'things that are important to me', 'keeping safe and healthy', and 'how I want to live'.

2. 'Making the Transition Plan, Year 9'

This stage covers details of the process of drawing up a transition plan in school year 9. It highlights the individuals that may attend the transition meeting and ways of informing others of the young person's aspirations. In particular producing a workbook is suggested as a way for the young person to communicate their current and future plans or any other topics they want to discuss in the transition meeting.

The end result of this stage is a transition plan that highlights what is to be done and who is going to be involved. It is important that the young person is aware that a plan is drawn up and that they should receive a copy of this plan.

3. 'Planning Ahead, Years 10-14'

The transition plan produced in year 9 should be received annually by the head teacher in a formal transition meeting. At these stages of the transition process the young person should already be participating in the goals highlighted from the last transition plan. The young person should be considering the aspects of the transition plan they enjoy and what they would like to change. This is subsequently discusses in the transition meetings between years 10 and 14 with appropriate adjustments being made.

4. 'Leaving School, Years 11-14'

Just before the young person is due to leave school (either 16 or 19 years of age), the transition plan should be reviewed again. The guide highlights the areas in the individual's life which the transition plan must have covered by this stage. This includes information regarding the individual's communication needs and their living and daytime activity arrangements. In addition the guide informs the young person of any assessments that may take place, who will carry them out, the reasons for these assessments and who to contact for more information.

5. 'Moving On'

This section outlines the future possibilities for the young person after school, such as residential colleges and employment. For those that may require continued support after school, the young people are informed that the Connexions PA offers support up until the age of 25. In addition a social worker, support worker or befriender can also offer support when the young adult leaves school.

Foundation for People with Learning Disabilities (2001) *Get Moving! Making a choice about where to live.* The Mental Health Foundation.

Functions of the Guide

This guide is specifically for those individuals who have decided that they want to move out of the family home once school has ended. The aim is to provide individuals with information of the variety of housing options available in order to make a suitable decision.

Key Messages

Four housing options, living on your own, living with family, living in a residential care home and living in sheltered housing are discussed. The extra support available in these different accommodations is explained as well as the types of support they offer.

The guide stresses the importance for the individual to be able to make a choice regarding their future accommodation and therefore provides some ideas that may help young people make the appropriate decisions for themselves. Individuals are encouraged to consider whether they would like to live by themselves or with friends and family, the types of accommodation they prefer, such as blocks of flats, and their particular support needs in their chosen accommodation. A variety of ideas are presented for young people to consider.

Young people are encouraged to talk to their friends, support workers and social workers about housing options and the types of support available for young people with learning disabilities.

Fyson, R., McBride, G., & Myers, B. (2002) *Strategies for Change. How people with learning difficulties are getting involved in changing services*. Norah Fry Research Centre, Bristol.

Functions of the Information Sheet

This information sheet is specifically for users of learning disability services and details the progress in service user involvement in local partnership board meetings. This follows the recommendations in Valuing People that service users and carers of individuals with learning disabilities should be involved when partnership boards plan and review services for them. The findings presented here represent the extent of service user involvement approximately a year after the government White Paper Valuing People was published.

Key Messages

The research team interviewed a variety of self-advocates from across England of their experience in attending Learning Disability Partnership Board (LDPB) meetings. The opinions of these service users is summarised according to their positive and negative aspects of attending LDPB meetings. These are summarised in the table below:

Positives	**Negatives**
Self-advocates were attending meetings	10% of self-advocates interviewed were paid to attend the meetings.
People with learning disabilities felt as though they were being listened to	The majority of individuals continued to have no say in the staff that worked with them or where they lived.
A few areas had people with learning disabilities on the interview panel for staff and managers of services	Transport to meetings was paid for by social services for only half of the self-advocacy groups interviewed.
Many individuals were also involved in training primary care staff.	Few LDPB supported written versions of minutes with symbols and pictures.
In 90% of places, minutes from LDPB	Few tape recordings of the meetings were

meetings were presented in a form relevant to the service user (i.e. in a big font).	available.

Implications for young people with learning disabilities and mental health problems going through transition

The first two documents published by the Mental Health Foundation discuss the experience of emotional changes during adolescence and equip young people with suggestions for maintaining emotional well-being. These guides recognise the vulnerability of adolescents with learning disabilities to mental health problems, thus offering suggestions specific to these problems. Therefore, many of the comments are important for adolescents with learning disabilities and mental health problems during transition.

Many of the suggestions emphasise the importance of sharing feelings with other young people, family members or a neutral contact such as a key worker as well as pursuing options autonomously. In this way the young person is prepared for adulthood through allowing them to choose the options best suited to their needs.

‘The Big Picture’ is important for young people of interest to our subject as the crucial stages of transition are clearly defined. The guide covers alternative ways in which an individual may communicate their future aspirations to professionals during transition meetings. These suggestions may be useful for young people with learning disabilities and mental health problems who may communicate using alternative methods. The input of a health worker is also introduced, so the young person is aware that these individuals are able to attend transition meetings and can help in addressing the individuals mental health problem. The predominant aim of this guide is to emphasise the importance of early planning, mainly for the individual and their family but also to the professionals that are often involved with them during this process. Although this guide is aimed at individuals with a range of disabilities, many professionals may find it useful to refer to this document. All those involved within the process should allow themselves plenty of time to prepare for transition meetings so that they are able to explore the range of post-school options.

‘Get moving’ is only relevant for those individuals that require help in making a decision about their future accommodation. It may be of use for an individual to be provided a guide such as this during a transition meeting so that they are aware of the housing options available and may instigate a desire to pursue this area further. Many of the suggestions allow the young person to consider the pros and cons of a variety of housing options. This guide may also be useful for the young person to communicate their requirements from future housing options to parents, local authority housing support services or during transition meetings.

The information sheet ‘Strategies for Change’ is important for individuals with learning disabilities as it promotes awareness of their role of contributing to Learning Disability Partnership Board meetings. Therefore, it is also relevant to individuals with learning disabilities and additional mental health problems. The information sheet highlights some of the problems continuing to face service users in their involvement with decision-making systems. Many individuals that are of interest to our subject will also face these same barriers identifies by this research project, as well as other barriers related directly to their mental health problems. Nonetheless, if the recommendations of Valuing People are to form the basis of future service provision, it is important that individuals with learning disabilities and mental health problems are also included or their views obtained through other methods. This may involve the individual providing their opinion on current and future service provision through picture booklets or other techniques which they are familiar with. A family member may also provide a report that summarises their relatives' views.

Whilst this information sheet is important for service users with learning disabilities, it highlights the progress that needs to be made to achieve inclusion of individuals with learning disabilities and complex needs in planning for services.

Part 4:A summary of selected guides and information sheets that inform a range of individuals supporting young people with learning disabilities and/or mental health problems

Foundation for people with learning disabilities, (2004) *Green light for mental health: How good are your mental health services for people with learning disabilities? A service improvement toolkit: Part a – The Guide.* The Mental Health Foundation, London.

Function of the Guide

This document addresses the developments mental health support services need to make in order to improve mental health support for people with learning disabilities, with reference to the expectations set out in the Mental Health National Service Framework (NSF) and Valuing People. The Mental Health NSF highlights what the government expects of mental health services for all adults of working age and therefore includes adults with learning disabilities. The government White paper Valuing people also discusses what the government expects of services for people with learning disabilities including those with additional mental health problems. Some of these expectations include:

Mental Health National Service Framework: 7 Standards.	**Valuing People.**
Mental Health Promotion through Social Inclusion	Inclusion of people with learning disabilities into mainstream mental health services.
Access to primary care that offers detailed assessment and treatment of mental health needs.	Specialist learning disability services to support individuals in accessing these mainstream services.
‘Round the clock’ contact with local services and NHS Direct for care of ‘common mental health problems’.	Resources for acute assessment and treatment available to local services.
‘Effective services for people with severe mental illness’.	Promote mental health in people with learning disabilities through making information and access to leisure opportunities, education, housing and employment more accessible.
Safe accommodation that is near to their home for service users that require care away from home.	All individuals with learning disabilities should have a Health Action Plan or one integrated in their CPA.
Ensure carers receive their own assessment of physical and mental health needs.	All plans should be person centred.
Prevent suicides through a culmination of the previous standards.	Reduce the number of out of area placement.
	Reduce number of in-patient admissions by specialist staff supporting individuals to access alternative services such a crisis resolution.

Parts (a), and (b) of this document discuss ways of incorporating government principles, service user and family carers wishes and putting them into practice.

This toolkit is aimed towards mental health local implementation teams and learning disability partnership boards as well as the young person, their carers and other professionals associated with them. By setting out the government's standards it is hoped that this document will:

- Allow people to identify areas that do not fulfil requirements in the mental health NSF and recommendations in Valuing people, within their local service.
- Provide a framework for implementing government policy into practice locally, to achieve a green light in their mental health services for people with learning disabilities.

Key Messages
Part a includes a summary of current policy regarding mental health services for people with learning disabilities, a service user version and outlines 13 key challenges that face current services in delivering the Mental Health NSF and recommendations in Valuing people.

An outline describing how each of the 7 standards identified in the mental health NSF may appear when applied to services for people with learning disabilities and mental health problems is also provided. A summary is provided for each of the 7 standards.

Standard 1: Health and social services should promote mental health in young adults. This can also include those with learning disabilities and mental health problems by:

- Enabling a Connexions worker, such as a Connexions personal Advisor (PA), to recognise and assess mental health problems in their clients who have learning disabilities. Additionally the Connexions establishment could develop guidelines for referral of their service users with learning disabilities that require mental health support.
- Mental health and learning disability services developing a joint strategy for mental health promotion that is specific to their service users with learning disabilities.
- Promoting social inclusion through having specialist learning disability staff support adults with additional mental health problems in accessing supported employment schemes, leisure activities and social relationships or any other mainstream service.
- Having a number of allocated places with specialist support allowing people with learning disabilities and mental health problems to access community mental health management sessions.

Standard 2: Improve the ability of primary health care teams to assess for mental health problems and refer to specialist services. A number of suggestions are made that include adults with learning disabilities:

- Having an information pack available to primary care teams that equips all team members with the ability to identify and respond appropriately to mental health problems in individuals with learning disabilities.
- ‘A single referral pathway’ to an agreed team of staff (i.e. a virtual team that combines professionals with learning disability and mental health experience) that is able to provide mental health assessments for those with learning disabilities.
- A member of the virtual team’ to ensure those with learning disabilities have received a health action plan.
- GP surgeries should develop a ‘flagging system’ where patients’ disabilities are displayed on the database, enabling staff to prepare for their arrival.

Standard 3: Individuals with common mental health problems should have access to ‘round the clock’ advice and local services. This includes access to NHS Direct. A number of suggestions are made that include adults with learning disabilities:

- A ‘virtual team’ be attached to mainstream ‘round the clock services’ and should consist of professionals with knowledge and expertise from both learning disability and mental health services. They should also have a ‘24-hour call service’.
- NHS Direct to have a referral pathway to local ‘virtual teams’.
- Individuals with learning disabilities and mental health problems and their carers should have access to an information pack that outlines sources of support for common mental health problems.
- People with learning disabilities and mental health problems should have a crisis plan with action points helping the individual understand what to do in a crisis situation.

Standard 4: For service users with severe mental illness the Care Programme Approach (CPA) should be implemented. The CPA includes a thorough assessment of the individual’s health and social care needs, involvement of the individual and carer in drawing up a care plan and access to a key worker. The overall aim is to improve the delivery of care and reduce crisis situations. A number of suggestions are made that include adults with learning disabilities:

- All individuals with learning disabilities and mental health problems should receive a person-centred CPA.
- This requires individuals from learning disability and mental health services that are trained person centred planning facilitators.
- Information about CPA must be accessible and relevant to people with learning disabilities.

Standard 5: Service users requiring a period of care away from home must be placed appropriately with consideration to their health and social care needs. Additionally, service users should be placed as close to their home as possible. The document includes a number of suggestions that consider adults with learning disabilities and mental health problems:

- In-patient provision for people with learning disabilities within mental health services. Specialist learning disability staff can support patients and other staff in providing appropriate care.
- Use local houses instead of hospital units for short-term in-patient provision. Staff from both learning disability and mental health services can run such provisions.
- Service users are provided with the option for intense assessment and treatment within their own homes.

Standard 6: Carers of individuals with mental illness should receive their own assessment of physical and psychological needs, of which they should receive a care plan. The document includes a number of suggestions that consider adults with learning disabilities and mental health problems:

- Carers of people with learning disabilities and mental health problems should have access to regular 'at home breaks'.
- Carers should also be supported in networking with other carers in similar positions to themselves.
- Individuals with learning disabilities and mental health problems should have access to supported holiday schemes that allow both the young person and their family member a break.

Standard 7: Ultimately reduce the rates of suicide in people with mental health problems through an amalgamation of all 6 standards. This document includes a number of suggestions that consider adults with learning disabilities and mental health problems:

- All members working with the individual must be aware of any history of self-injurious behaviour.
- Learning disability and mental health services should have common risk management protocols, so that they respond effectively in a crisis situation.

The final section of this document discusses the self-assessment checklist its uses and ways of establishing the improvements that are required in each area. Ultimately, the checklist is useful for local implementation teams in order to assess how well services are implementing the seven standards in the mental health NSF. Also discussed are ways in which local services can obtain evidence of local service provision before filling out the checklist.

Foundation for people with learning disabilities, (2004*) Green light for mental health: How good are your mental health services for people with learning disabilities? A service improvement toolkit: Part b – The Tools.* The Mental Health Foundation, London.

Function of the Guide

This part of the 'Green light' toolkit concentrates on introducing the self-assessment checklist. It is to be completed by both learning disability and mental health services in partnership, where red, amber or green lights are to be attached to the statement that best describes local provision. It is ultimately of use for local implementation teams to extrapolate how well the mental health NSF is implemented for people with learning disabilities.

Sections 2 to 4 of this document include surveys of in-patient, community support and carers experiences. These surveys are provided to aid implementation teams and partnership boards in establishing the improvements that are required in each area. Advice is provided regarding the best ways to carry out the surveys on service users and their carer's real experiences and in obtaining their opinions on the support and opportunities available

Key Messages

Self-Assessment checklist

The checklist covers a range of areas that helps identify current improvements and allows services to monitor changes in service provision over time. These areas includes 'local partnerships', 'local planning', 'access to services', 'joint working', 'key services', 'care planning', 'diversity of provision', 'underpinning programmes', and 'other priorities'. After each of these sections is displayed there is space for any extra comments, which a service provider may wish to contribute.

The proforma summary and action-planning sheet allows the service provider to summarise the green, amber, and red light areas for local implementation teams. This section also encourages the service to identify 5 key development priorities and to summarise ways to achieve improvements in the areas identified.

Survey of in-patient experience

A sample copy of the survey and advice when interviewing people with learning disabilities and mental health problems is provided. This survey is aimed towards describing in-patient generic or specialist mental health units. For example, an interviewer may ask the service user about the in-patient environment, or whether it was near to their home. The second part of the survey aims to identify the service users perspective and opinions on their own experience. For example, whether they liked the environment they occupied.

Practical advice around interviewing people with learning disabilities and mental health problems includes:

- Ensure the person understands the purpose of the survey and has consented to take part.
- Make sure the person understands confidentiality.
- Use clear questions and avoid jargon.
- Ask them when and where is suitable for them to take part in the survey.
- Read back their answers so they know exactly what has been recorded and are confident that the comments are a true reflection of their experiences.

Survey of community support experience

The advice provided is similar to that in the in-patient section. This tool aims to gain a description of community support for from the perspective of a person with learning disabilities and mental health problems. This includes support in day-to-day life as well as support with their mental health problems. In addition service users are asked of their opinions of their particular experience, i.e. what was good/bad about it and why.

Survey of carers' experience
This survey asks carers of people with learning disabilities and mental health problems about their experience of obtaining information and advice, support and about their involvement with their family member.

All surveys outline what people with learning disabilities and mental health problems and their carers have previously stated as important in their lives. The surveys aim to compare this with the actual experiences of these individuals in obtaining support for mental health problems.

Implications for young people with learning disabilities and mental health problems going through transition
Though, not relating to the transition process this document has important implications for adults with learning disabilities and mental health problems that require a considerable amount of support once they have advanced the formal transition process.

It aims to provide a way of establishing current mental health support for individuals with learning disabilities, as well as identifying the expectations of mental health services set out in policy documents. This method highlights the improvements that are required to obtain the service needs of individuals with learning disabilities.

It would be useful to include the opinions of individuals entering the transition process regarding their future mental health service needs. Local implementation teams and partnership boards could incorporate this information to improve future services for people with learning disabilities. Representatives from education, Connexions and social services could also help in determining the opinions of these young people and passing on relevant information to implementation teams and partnership boards.

Mallett, R., Power, M., & Heslop, P. (2003) *All Change. Transition into adult life – a resource for young people with learning difficulties, family carers and professionals.* Norah fry research centre. Bristol.

Function of the Guide
This guide was written to provide families, professionals and young disabled people with information about the various choices and options available after leaving school. The adult and service user versions that are included in this document also cover the roles and responsibilities of relevant parties in the process of drawing up and reviewing the transition plan. Additional advice is also provided of ways families and young people can ensure the transition planning process meets the principles of the SEN Code of Practice so that it is 'participative, holistic, supportive, evolving, inclusive and collaborative'.

Key Messages

The adult and service user versions each contain a number of useful messages regarding the process of transition. Both versions are split into 5 chapters that cover 'Planning for Transition, Changing Roles, Choices for the Future, Using adult services and Living Life to the Full. The key messages in each chapter are summarised.

Chapter 1. Planning for Transition

This chapter allows any supporter (including the family) of a disabled young person, to prepare both before and after the year 9 transition review meeting. It sets out the purpose of the Year 9 review as well as outlining who must attend and ways the young person can receive the most appropriate support. For example, it is advised that the Connexions Personal Advisor (PA) and a social worker visit the young person before the Year 9 review in order to assess the likely future needs of the individual.

After the year 9 review, it is the duty of the Connexions PA to 'oversee the delivery of the transition plan' and ensure all post-school provisions that have been discussed are explored before the next transition review meeting.

This chapter appears relevant for any professional that has supported the young person in the past or who may be involved with the young person in the future. At the end of the chapter, there is a checklist aimed specifically towards parents to help them identify their young persons wishes for the future as well as their information requirements during the transition process.

Chapter 2: Changing Roles

This chapter discusses the impact of a young person reaching the age of adulthood on the young person as well as their family. Many parents often find that, as their child with learning disabilities becomes an adult their roles change from parent to carer and this is reflected poorly in the support and advice they receive from external sources of support. This chapter discusses the continued importance of the family, including parents, grandparents and siblings in supporting the young child into adulthood and the support they are entitled to fulfil their role.

Valuing people recognises that parents require 'more information and support, a better assessment of their own needs, improved access to short break services and respite and should be considered as valuable partners to professionals in supporting the young person'. This guide covers some of the existing local authority and voluntary services available for carers to maintain their own well-being. It discusses the carers right to a carers needs assessment through their local social services department, direct payments and short break services including residential short breaks, home care services and sitting services.

Similarly, for a young person with learning disabilities the transition process can be confusing, demanding and lead to heightened stress and anxiety. The last part of this chapter discusses ways to ameliorate the experience of anxiety for the young person during transition by:

- Ensuring they are fully supported to be involved in making decisions for their future.

- The young person may require the help from an advocate, circles of support, Connexions PA or someone outside of the family to discuss their dreams for the future.
- The young person should have access to all the relevant information in order to make an informed choice for their future.
- All services should adopt a person centred approach in their planning that accommodates the young persons preferences.

Chapter 3: Choices for the Future
This chapter covers four of the many post-school options available to a young person. These options include further education, work, daytime activities and living. Within each post-school possibility a range of options are discussed, as well as the factors to consider when making these choices.

The first option considered is further education. All individuals have a right to full time education up until the age of 19. For people with learning disabilities, there are a number of further education considerations to be made. This section is particularly useful for families or teachers of the young person as it identifies the range of possibilities available as well as providing useful ideas of getting to know the types of courses that may be of interest.

Choosing a further education college or residential college can be difficult for the young person and their family and they require as much support and time as possible to ensure they choose the most suitable places. The Connexions PA can help families and the young person during this time. The families themselves can also arrange visits with a range of colleges to help their son or daughter pick the right place. Additional advice is also provided to help parents and the young person apply for a place at college. Parents are also made aware of the types of financial and personal support available for their child at college.

The second option considers employment possibilities for people with learning disabilities and the support available in finding and maintaining a job. It is mainly the Connexions PA and Disability employment advisor that will be able to provide advice and information on training opportunities and supported employment schemes. The possible work options discussed include supported employment, social firms, voluntary work, and open employment. This section highlights the adjustments many of these options can make to ensure that a person with learning disabilities can manage the tasks and ultimately gains in self-esteem and confidence. For example, some agencies encourage ‘job carving’ where aspects of other jobs are created into a manageable job for a person with learning disabilities. Mentors can also be assigned so the individual is supported in their employment. This guide also identifies that transport to work can be a significant barrier for a young person in taking on employment. The Access to work scheme that assists in transporting individuals to work is explained as well as the complications around access to benefits for disabled individuals that take on work. Useful contacts are provided for families to obtain more information relevant to their situation.

The third option discusses the range of daytime provision for people with learning disabilities. This includes access to modern day services that allow the individual to develop their social skills as well as enhance their education and employability. All programs arranged for the individual should make the most of their interests and capabilities, and so adopt a person centred approach. Parents are advised to visit a range of day centres in order to find the provision most suited to the individual.

The final option discusses assessment, funding and benefits for a number of housing and support options. The options discussed in this guide include ‘staying in the family home, adult placements, supported lodgings, supported living, registered care and intentional communities’. Each option is described with information of Housing and Council tax benefits, direct benefits and Independent Living Fund the young person may be eligible to. In most instances the family are directed to contact their local social services department for further advice and information for community care assessments. A checklist is provided for both support staff and family carers as they are all in an ideal position to find out the young persons desires about future accommodation.

Chapter 4: Using adult services

This chapter discusses the organisation of social services and health services and describes the types of services and support that they provide. There is a particular emphasis on their role in providing assessments (i.e. community care assessments and health action plans) during the transition process.

If a family and a young person are assessed as requiring community care and support, families may be charged to use some of the services that are recommended. This chapter therefore discusses ways families and the young person may use direct payments and Independent Living Trusts in order to choose the types of services they require.

The section covering health services discusses the mental health needs of people with learning disabilities. GP’s, parents and Health action plans are discussed as important in the context of detecting and promoting positive mental health in the young person. This section ensures parents and professionals are aware of the susceptibility to mental health problems for people with learning disabilities and also the need for appropriate assessment and support from community mental health services. It recommends that mental health support be discussed during transition planning meetings.

A final section covers methods of making an appeal or complaint regarding any of the provisions made for the young person and their family. This includes entitlements to benefits for housing, allowances for travel as well as decisions regarding direct payments and Independent Living Funds. It covers the procedure for making an appeal as well as the support families can get during the complaints process.

Chapter 5: Living Life to the Full

This chapter attempts to address the many concerns parents face of the decline in their young persons social networks, social activities and personal relationships once the transition to adulthood has been achieved. Discussed are ways for young individuals to maintain their social networks through becoming involved in group activities, self-advocacy groups and circles of support. It is important that the transition plan identifies the young persons wishes to remain in contact with their childhood peers and provision future services so that these contacts are not lost. This includes having the young person stay in the same geographical area as their peers and relatives or aiding them to remain in contact with friends and family through assistance with letter writing, sending e-mails and text messages.

Many young people with learning disabilities have exaggerated the importance of leisure activities and opportunities in their lives. This chapter discusses the variety of specialist and non-specialist schemes available in many local authorities. Parents and families are advised to contact their own local authority for information on concessionary schemes.

As well as changes in friends many young individuals may begin to develop personal relationships. This is often a source for concern for many families. This chapter discusses the need for young people with learning disabilities to access appropriate sex education and advice on sexual health matters. A list of information materials is provided.

Service User Version
This section of the guide is written in a format accessible for many young adults with learning disabilities. Each chapter covered in the guide for families and professionals is reproduced for the young people. The most important and relevant information has been taken to inform young people of the transition process, their rights and responsibilities as well as the possibilities they may want to explore for their future.

Scholl, C., Dancyger, F., Parsons, M., & Dale, C. (2005) ***Transitions Pathway. Guidance and tools to support person centred transition planning with young disabled people aged 13-25.***

Functions of the Guide
This guidance booklet is aimed towards any individual involved in transition planning for a young person with a disability. It aims to promote some good practice initiatives from the West Midlands as well as improving the experience of transition planning for young individuals and their families. Much of the guidance aims to achieve this through adopting person centred approaches in obtaining the views of the young people and their families.

The process of transition is divided in five stages to allow the young person and their family achieve their wishes for the future in a manageable, stress free manner.

Key Messages
The guide identifies Stage 1, as the time between school years 8 to 9 where a young child with a statement of special educational needs should be preparing for the transition process and first transition meeting. The guide highlights government and good practice guidance specifically for this stage of the process. Of particular relevance is the duty of each Local Education Authority (LEA) to notify the Connexions service of the number of children requiring year 9 reviews. This allows the connexions to assign personal advisors to each individual so that they are able to form relationships with the family. The good practice guidance particularly informs educational professionals of the initiatives they can adopt in order to help members of their class prepare for the first transition meeting. Some of these initiatives include:

- The schoolteacher sharing information with the young person about transition and ensuring the young person understands the process.
- The Connexions personal advisor introducing themselves to the family and the school.

The guide promotes the use 'Getting Ready' sheets to allow the young person and their family prepare the areas they would like to cover in the transition planning meetings. These sheets are useful in that they can be taken into transition review meetings and so remind the young person and their family of the specific topics they want to discuss. These sheets cover all aspects of a young persons life. A checklist for Stage 1 is also provided for various professionals and parents to monitor what should be happening at this stage of the process, who is fulfilling a particular role and how it is to be done. This enables individuals to ensure all required activities have been addressed or completed.

Stage 2 is defined as the period where the Transition plan is drawn, and should occur in school year 9. Government policies indicate that for a child with a statement of special educational needs the head teacher or special educational needs co-ordinator (SENCO) must lead a transition plan meeting in year 9. In addition, they must invite any person who may be involved with the young person, such as a social worker or psychologist, but must invite the Connexions PA, the family and the young person. Of integral importance to the year 9 planning meeting is that the young persons views are sought after and they have the opportunity to voice their preferences. Good practice highlights that successful transition planning meetings are those where:

- The young people have the opportunity to advocate for themselves,
- The young person is provided with a range of accessible information on transition planning and future possibilities,
- Fulfilling the wishes of the young person is at the forefront.

The guide highlights the importance of the 'Getting Ready' sheets as a way for the young person to prepare for transition meetings and to share their views with others present at the meeting. Information collected from a transition meeting may also be added to these 'Getting Ready' sheets so that the young person is able to keep a record of what was discussed at the meetings. A checklist is also provided, so that the young person and their families may keep a record of the action points decided at the meeting, who was to fulfil that role and how it was proposed to be fulfilled.

Stage 3 occurs between school years 10 to 14 and is dedicated to 'planning ahead'. The Special Educational Needs Code of Practice (2001) states that 'the head teacher has the responsibility for organising a review meeting at least annually'. This allows the young person and their family to discuss aspects of the transition plan that are working well as well as those that the individual does not enjoy as much. It remains important to involve the young person in the review meetings and actively to seek their opinion. Good practice initiatives also highlights,

- The importance of presenting the individual with a range of opportunities so that they are able to make an informed decision of the provision that best suits their abilities.

- The young person should be supported to develop skills for adult life, such as advocacy and independence.

The 'Getting Ready' sheets can be useful for the families and young person to review action points from previous meetings and highlight areas that they want to discuss further. All aspects of the young person's life should be reviewed and any changes in the young person's point of view should be explored.

Stage 4 covers schools years 11 to 14 and provides advice for the last transition review meeting before the young person leaves school. It is important at this stage for families and professionals to ensure that any assessments the young person or family may require have been completed by the last year of school. This includes assessments of future employability and need for social services. The good practice initiatives highlight:

- The need to have the final transition-planning meeting early in the school year. This allows for any final adjustments to be arranged before the child leaves school.
- Seek consent from the young person to share their transition plan with any future providers.
- The Connexions PA should make sure the individual understands that they are leaving school and knows where they are going.
- Discuss with the young person how they may continue to plan for their future.

The final stage of transition discussed in this guide provides advice on planning once the young person has left school. The 'Getting Ready Sheets' are useful for the young person to continue to use when they plan various transitions in their adult life such as changing college, jobs or housing. Some good practice guidance sheets are provided for the young person to take to local colleges, residential colleges, training providers, daytime activity providers and employers. This promotes awareness of practical initiatives future providers can use in order to support the individual with a disability.

The final chapters of this document provide samples of other transition plans, and 'getting ready sheets' for individuals and their families to refer to if they are experiencing difficulties with filling in the sheets provided with this document. Also included are templates of letters that a young person, SENCO, or Connexions PA may use to invite professionals to transition review meetings.

Implications for young people with learning disabilities and mental health problems going through transition

Both the Transitions pathway and All Change guides are very important for all individuals involved with young people with learning disabilities and mental health problems. They both outline the important stages of the process, what government policies state and evidence good practice initiatives across the UK. There is also a certain amount of overlap between the two documents and their key messages correspond with each other. The main aims of both documents are to overview the ideal transition process, explaining some possible barriers along the way and ways for all individuals involved to overcome these barriers. They both offer realistic ways of proceeding through the transition process and overcoming some potential obstructions. Unlike, many other guides, these guides emphasise the theme of a shared responsibility between families and professionals in transition planning and continued post-school support. Many of the key points are relevant for any individual and are not directed to a specific person.

Both guides are aimed at an audience of professionals and families of any disabled child. There are many points particularly relevant for individuals with learning disabilities and mental health problems. There is also a strong emphasis on maintaining a positive mental well-being throughout the transition process.

Morris, J. (2002) *Foundations. Moving into Adulthood.* Joseph Rowntree Foundation, York.

Function of the Information Sheet

This information sheet draws on the findings from a variety of research projects that concentrate on the pitfalls in transition planning for young disabled adults. It summarises the various barriers identified by different research projects, for young disabled people in becoming fully autonomous adults. Though the exact audience of this document is not stated, it appears useful for any individual involved in transition planning, particularly Connexions Personal advisors, as it identifies the necessary improvements required to make transition for a young person an inclusive process.

Key Messages

Making Choices: barriers and practice initiatives

The literature covered in this document identifies that many individuals with statements of special educational needs have not received a formal transition plan after the age of 14. Individuals that do experience a formal transition meeting to discuss future provisions, face inadequate transition planning of their needs. Many young people feel uninvolved in the decisions made regarding their future, are disappointed with the limited choices presented to them and the unsuitability of what is available. For individuals with severe communication and cognitive impairments, their involvement and range of choices becomes more circumscribed.

Another failure of transition planning is the deficit of information provided to the family and young person. This has been suggested to occur for a number of reasons. Many young individuals pre-transition possess a named professional in school whom they can seek advice and information from. This important individual is usually lost in the transition to adulthood and rarely replaced in time to be of use for the young adult during transition. Families and parents are often another source of information for young people, but the literature highlights the lack of accessible information even for parents during transition. It appears that information sharing between professionals and the young person and their family is hampered as a result of a failure of professionals to understand the young person and their likes and dislikes. In many cases it is assumed that the family are automatically the main information finder and advocate for their young person. For many individuals this may not be the case.

A number of suggestions has been provided to improve transition planning for young disabled people.

- Ofsted and local education authorities must ensure local schools are aware of the requirements, under the SEN code of practice, for transition planning to commence in school year 9.
- The Connexions PA should receive Disability Equality training so that they understand the barriers facing many disabled people, and can work in partnership with the young person in reducing these barriers.
- Identify the young persons goals and possible barriers to these goals.
- Identify initiatives in providing thorough information to the young person and of achieving independence.
- Multi-agency planning can provide the young person with a comprehensive range of future options.

Further education, training, work and housing: barriers and policy considerations

Individuals that require a high level of support have experienced limited further education, training and paid work placements post-transition. It is suggested that this results from the lack of a national agreement in funding for post-school opportunities for disabled individual. Many professionals also possess low expectations for individuals with disabilities and therefore often do not include further education or employment on their agenda for transition planning. In addition, much research has identified many mainstream and special needs schools and colleges are lacking in knowledge of the opportunities for post-school work training and employment.

Housing arrangements made for disabled people also vary considerably with geographical area. This document highlights that many housing decisions are based on ‘current vacancies rather than by the young persons choice’. Often, many of the young persons preferences are limited to residential care homes as the desired accommodation is either inappropriate for a disabled person or is unaffordable.

Much of the policy on post-16 training and work is highlighted so that readers of this document are aware of the rights of disabled people and of the responsibility of various agencies in promoting schemes that aim to reduce the barriers for disabled individuals in obtaining paid employment or a home of their own.

Implications for young people with learning disabilities and mental health problems going through transition

This information sheet appears important for families and professionals involved in transition planning for individuals with learning disabilities and mental health problems. It covers the relevant research on transition planning and summarises possible causes for poor transition planning. It serves as a useful reminder for professionals to ensure that they take into account the views of the young person and highlights the possible effects of a failure to involve service users, such as low confidence and self-esteem. Professionals must also ensure they have access to a range of information on post-school options, and be unbiased in the information they share with young people and their families.

For families this information sheet informs them of their rights as well as the rights of their relative under the Disabled Persons Act 1996, NHS and Community Care Act 1990 and Chronically Sick and Disabled Persons Act 1970.

Part 5:A summary of guides and information sheets for individuals involved with young people with an Autistic Spectrum Disorder.

National Autistic Society (2004). Breaking down barriers to learning: Practical strategies for achieving successful transition for students with Autism and Asperger syndrome.

Functions of the Guide

This guide is intended specifically towards teachers of children with Asperger syndrome and statements of special educational needs. It focuses on the transition of these individuals from primary to secondary mainstream education and promotes useful strategies to employ to achieve a smooth transfer that does not affect educational and social progress. In this case the term transition refers more to a single point transfer of responsibility from primary school teachers to secondary school teachers. Transition that is referred to in our subject relates more to the process of moving from child-oriented services to adult-oriented services.

The strategies that are suggested here have been the result of a research project that interviewed students, parents and teachers and focuses on social and curricular difficulties of these students.

Key Messages

An overview of useful strategies to use in the school years preceding secondary school is provided. Many of the key messages from this guide can be generalised to transition for young adults to adulthood. There is an emphasis on early planning and preparation particularly for these students, as they require structured environments. It is also recommended that in Years 5 and 6 students become accustomed to new teachers and different environments and for primary and secondary school teachers to establish relationships and brainstorm new effective ways to work with the children. The knowledge of parents and good communication between the school and parents is stressed at all stages of the process.

The remainder of the guide focuses on specific difficulties that students with Asperger syndrome experience and suggests some important strategies. These difficulties include ‘social’, ‘communication’, ‘organisational’, ‘sensory’, ‘behaviour’ and ‘homework’. The key messages for each of these difficulties are summarised in the table below.

Difficulty	**Strategy**
Social • Students find working in pairs or in small groups difficult. • Many have problems with turn taking in social situations and therefore interrupt others when talking.	• Social scenarios can be modelled to the individual in a way that is relevant and interesting to them (i.e. use cartoons and short stories). • Identify a structured set of social rules. • Use the other children to help model social situations.
Communication	

• Many students have difficulties in processing oral information in order to filter important components of a conversation. • This results in an inability to follow instructions clearly.	• Break down the conversation into small manageable chunks and check for understanding at regular intervals. • Write down instructions on a white board for students to check off once the task is complete. • Speak slowly and clearly always addressing the pupil.
Organisational • Students vary from being meticulously organised to extremely unorganised for lessons.	• Draw up a checklist of items for students at home and at school so they are aware of the books and stationery required for school and home.
Sensory • Sensory, olfactory and auditory processing difficulties may result in non-attendance for some lessons or leaving lessons without permission.	• Reintegrate the individual to the new environment by having a designated waiting area for students just before school, to avoid the big crowds. • Allow the student to leave a few minutes later or earlier to avoid crowds. • Be aware of their difficulties and adjust seating arrangements in the classroom to accommodate for the individual.
Behaviour • Much of a child's challenging behaviour results from their sensory, organisational, social and communication difficulties. • The resulting behaviour may manifest as withdrawal from social situation ranging to angry outbursts and aggression.	• Determine the cause of the behaviour. • Break down the task into achievable parts. Reward the completion of these tasks. • Provide a space for the child to be by themself.
Homework • Student may have difficulty in starting or completing homework due to a lack of motivation, lack of understanding what is required or difficulties in forward thinking.	• Explain why homework is important using a social story. • Have the teaching assistant explain the homework to the child and vice versa. • Have the teaching assistant help the child set out a framework for completing homework.

Implications for young people with learning disabilities and mental health problems going through transition

Though this document does not address the transition from children's to adult's services, much of the information concerning children on the autistic spectrum is necessary for teachers to be aware of. This document highlights the importance of preparation, early partnerships between schools, and information sharing when working with children with Asperger syndrome. Much of this key information is also relevant when transitioning young adults with Asperger syndrome as well as other individuals with statements of special educational needs.

The document focuses on educational and social difficulties that need extra consideration when a child moves school. The strategies suggested are specifically aimed for children and therefore would require updating to make them relevant for young adults. For example the use of social stories and cartoons to explain appropriate behaviour in social situations would not always be useful when preparing individuals that are entering adulthood. However, the advice provided to help students organisational skills can be applied to transition into adult services.

Morgan, H., Jones, G., & Jordan, R. (2001*) Autistic Spectrum Disorders. A Guide to services for Adults with Autistic Spectrum Disorders for Commissioners and providers.* Foundation for People with Learning Disabilities, London.

Functions of the Guide

This guide was written with professionals and commissioners of services for adults with autistic spectrum disorders in mind. In addition, this guide aims to help those seeking information on the types of services available for adults with autistic spectrum disorders, such as GP's, nurses and families.

Commissioners of services are often unable to meet the specific requirements of individuals with autism due to an inadequate knowledge of the nature of autistic spectrum disorders as well as the inability to use limited resources effectively. By presenting the definition of the term autistic spectrum disorder and the categories that fall under the spectrum, it is hoped that commissioners are better able to understand the variances in symptoms around the core triad of impairments and therefore are better equipped to commission services based on individual need.

Key Messages

Figures provided by the National Autistic Society indicate that between 35 and 91 per 10,000 of the population are diagnosed with an autistic spectrum disorder. These prevalence rates vary according to the way the criteria established in DSM-IV and ICD-10 are applied. Therefore, many who do not meet the criteria may equally require access to individualised services as those who have gained a formal classification.

A wide range of services provided from public, voluntary and private sectors, currently exists for adults on the autistic spectrum. In addition a wide range of national and regional societies such as the National Autistic Society, Autism Initiatives and NoRSACA are in operation consisting of many parents and service users. This guide provides a list of principles on which these services should be based, if they are not already:

- A service should plan their provision for adults with autistic spectrum disorder in advance and always take into consideration the individuals need for consistency and reluctance to changing environments. In short, a service for adults catering for individuals with autism must be autism friendly.
- The individuals' needs must be attained through person centred approaches.
- Services should be planned flexibly to take into account the current and future needs of the individual.
- A service must seek and take into consideration the family's experiences.
- Staff must have intensive training on autism so that they approach individuals in the appropriate manner.
- A service must practice all possible forms of alternative communication.
- A service must be accredited through Autism Services Accreditation Programme (ASAP).

It would be useful for a commissioner to have a list of questions, that include some of the above points as well as other points specific to the individual for whom they are commissioning, in order to provide a service that meets the individual's requirements. In addition, possible future services must make clear the boundaries within which they work, so that commissioners can confidently state what can realistically be provided.

Implications for young people with learning disabilities and mental health problems going through transition

Many of the individuals of interest to our project may fall under the category of an autistic spectrum disorder. It is important that their needs are recognised as separate to other individuals with learning disabilities and also that the presentation of a mental health illness may also differ. This guide recognises that many commissioners of services may confuse learning disabilities with autistic spectrum disorders. Although in many cases the needs of individuals with learning disabilities and autistic spectrum disorders are not dissimilar, many individuals require unique services.

This guide provides a useful overview of the principles upon which commissioners should provide services for individuals with autism. It is imperative that commissioners not only understand the nature of autism but also are aware of individual's specific requirements. The transition process is therefore an important stage for commissioners to identify these requirements. This guide recognises the importance of sharing appropriate information that is a true reflection of the individual's desires for future services. This allows services to be commissioned according to the needs of individuals and not on availability of services.

Harker, M., & King, N. (2004) Tomorrows Big Problem. Housing options for people with Autism. A Guide for service commissioners, providers and families. National Autistic Society.

Functions of the Guide

There is a need to recognise autism as separate and distinct from other disabilities including learning disabilities. Therefore, policy establishing the provision for adults with learning disabilities must also address adults with autism as a separate category. To date, there is very little advice and information on housing options for families and the young person. Whatever information is available fails to consider the wide range of types of individuals with an autistic spectrum disorder. Therefore, a particular service option will not be adequate for all adults with autism.

This guide focuses specifically on the transition of a child with autism from the family home to their own home. Due to the high support needs of many individuals with autism, there is a danger that many young people continue to live in their family home or receive little support in the move from one home to another. As a result, the transition to independence for adults with autism is impeded and may result in additional anxiety for all that are involved. This guide is based on research looking into:

- 'How housing and support needs are currently being met',
- 'The need for a range of housing options for adults with autism',
- 'The views of local service providers from housing, health and social services'.

In order to obtain these research objectives the views of service providers, commissioners and families is sought.

The messages from this guide are particularly pertinent to service providers, commissioners and managers of future housing provisions. The overall aim is to marry the views of service users and their families with the objectives in Valuing People of 'enabling people with learning disabilities and their families to have greater choice and control over where and how they live'.

Key Messages

The key findings from the interviews and their implications on services for individuals with autism are:

'How housing and support needs are currently being met'

- Since 1971 there are ten times more supported accommodation services for people with learning disabilities.
- Less than a quarter of those with learning disabilities are on the autistic spectrum.
- Interviews from families and providers found limited numbers of places allocated for adults with autism. Many individuals are presented with little option but to live at home.
- Findings found about a third of individuals with autism and learning disabilities are supported for in accommodation.
- Those with severe and challenging behaviour occupy much of what is available.

'The need for a range of housing options for adults with autism'

- There is a variety of housing options and support available for disabled people.
- However, most individuals with autism continue to live in the family home as parents find they have limited options presented to them at transition.
- Many local areas are not able to serve people with autism and Asperger syndrome.

- Many individuals with autism and Asperger syndrome do not meet the services definition of need and are also often referred to residential services away from home.
- Early planning (preferably beginning when the child is still in education) will allow people with autism to choose where they want to live.
- Those involved in planning of future housing provision (i.e. social services and housing departments) should have mechanisms in place that allow them to carry out joint assessments of need.

‘The views of local service providers from housing, health and social services’

Greater attention needs to be allocated to local strategies so that they reflect the needs of individuals with autism. A local survey of the future needs of adults with autism needs to be carried out. To date the statistics reflect the needs of children that have received a diagnosis. The needs of adults with autism are either not established or lost in the learning disability statistics.

Establishing a profile of local area needs for a service and identifying the number of existing services available would allow commissioners to confidently plan for services and provide families and individuals with options that can definitely be provided for.

Many of the case studies, that evidence good practice initiatives, emphasise the importance of provider services to:

- Include individuals with autism in planning services,
- Establish partnerships with local authorities and voluntary agencies,
- Offer a range of services such as outreach and community support.
- Plan for all stages of an individual’s life, including their choices and options as an adult user of services.

Implications for young people with learning disabilities and mental health problems going through transition

This guide establishes the need for a commissioner to understand the views of families and local service providers, particularly when commissioning housing services and support for adults with autism. It is these individuals that possess an understanding of the current need for housing options and allow the commissioner to change their direction for future planning of services.

The opinions of individuals with autism that are currently going through the process of transition would be valuable for commissioners to seek guidance of future needs of housing services and support. At transition, it would therefore be important to seek guidance from the individuals and their families as well as ensure that their views are passed on to providers of services. The range of service requirements of individuals with autism could similarly be obtained using some of the messages obtained in this document. For example, commissioners of day services would similarly benefit from a survey of what is currently available. In addition, they would need to identify the daytime needs of individuals and families expressed at transition and the views of service providers from health and social care.

Tarleton, B. (2002) ***Better for the Break. Support for children with Autistic spectrum disorders and their families*****. Norah Fry Research Centre, Bristol.**

Functions of the Information Sheet

This information sheet summarises the results of a study looking into the use of short breaks and family support services such as family link services, residential short breaks, sitting schemes, befriending schemes, outreach services, play schemes and after school clubs for children with autistic spectrum disorders (ASD) and their families. Of particular interest was whether short breaks were appropriate for children with ASD, which were used most and what improvements needed to be made to make short breaks appropriate for children with ASD.

Key Messages

The national survey into the use of short breaks revealed 'a quarter of children using short breaks have ASD, with the waiting list of short breaks consisting of a third of children with ASD'. Interviews of 6 adults with ASD revealed short breaks were beneficial for children with ASD as long as the services provided understood the nature of ASD and recognised the specific needs of the child. Families reiterated the adults' view of the benefits of short breaks in experiencing new activities and relationships.

However, access to these short breaks was often prohibited by lack of available services in the local area, limited funding and lack of supporters willing to work with children with ASD. This latter point reflected the lack of awareness of ASD among frontline staff and supporters and the need for training and awareness of ASD. Families also expressed a desire for flexible packages of support for themselves as well as their child that was available throughout the year. This requires considerable increases in funding of services.

The project discovered six key points to consider when providing appropriately for children with ASD. This includes 'knowing the child and their views, respecting the parents and developing their trust, multi-agency working in order to achieve a flexible package of support, providing the individual with a feeling of control and a safe environment, and supporting involvement and development.

Implications for young people with learning disabilities and mental health problems going through transition

The six key points identified as a result of research into short breaks for individuals and families with ASD are also important points for individuals to consider during transition. This information sheet highlights the need for a range of services to be offered during and after transition. In addition, service providers must be aware allow time to develop an understanding of the family and the individual.

It is important for service providers to bear in mind the themes of support and inclusion that dominate the research on transitioning services of young people with any disability to adulthood. The lack of support and rights to inclusion for some vulnerable individuals, such as individuals with learning disabilities and mental health problems, can have adverse effects on the individuals overall quality of life.