

Understanding mental capacity and marriage

A booklet for parents of someone with a learning disability

My Life, My Marriage Project
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RESPOND))
from hurting to healing

Understanding mental capacity and marriage: a booklet for parents of someone with a learning disability

For many parents it will be helpful to go through this booklet with a professional. Some parents will also need an experienced interpreter to be present.

We hope that this booklet helps parents understand about mental capacity, marriage and how this all links to forced marriage. We hope that it will encourage discussion between parents and professionals and also within parent support groups.

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This booklet used imagined stories and any similarity to real people is a coincidence.

1. What is a learning disability?

This is sometimes now called an intellectual disability. Assessments or observations in childhood have shown that your son or daughter:

- Has a significant difficulty in learning and using information (difficulty in intellectual functioning) **and**
- Has a significant difficulty in doing the kinds of things that we need to do to look after ourselves and others safely without a lot of support (difficulty in daily living skills and adaptive behaviour) **and**
- These were present through your child's development to adulthood, usually from birth onwards.

2. Having a learning disability and getting married

A person with a learning disability who can decide for themselves about something (has the capacity to make that decision) has the same right to have that opportunity as anyone else.

It is important that people with learning disabilities and have capacity to consent are supported to get married if they wish to do so and are not put under any pressure to marry.

For consent to be legally valid the person giving it must have the capacity to make the decision, have been given enough information to make the decision and not have been under any pressure or threat of harm.

A marriage of someone with a learning disability who has capacity to consent and gives that consent freely is recognised as a valid marriage. This includes marriages arranged with the support of the family.



3. Families where there is someone with a learning disability

For all families where there is someone with a learning disability it is important to plan for the future in a way that looks carefully at what support that person needs at every stage of their life.

It is important to talk as a family and with your son or daughter as they are growing up about their disability and their strengths and weaknesses. It is important to find out what they understand and about their future wishes.

It is also important to think about what the family expect the person will be able to do when they are an adult. This is not only about marriage and having children but also about other things such as education, positive activities and work.

It is important to think about whether or not the person has capacity to make decisions and consent in important areas of their life.

Being a parent of someone with a learning disability

When a young person with a learning disability is growing up and in education like other young people, there may be a strong hope that he/she will grow out of their disability.

Sometimes the person with the learning disability may say they want to get married.

Wanting to be a good parent can mean that parents think the young person with a learning disability will get married like other adults.

There may be a belief that a person can learn about being married by doing it.

Thinking about your son or daughter getting married means thinking about their capacity to consent.

When a person with a learning disability does not have capacity to consent to marry they cannot legally marry.

Reasons that parents think about marriage

Thinking that your son or daughter with a learning disability should always get married can be linked to:

- Wanting to support their wishes
- Wanting them to be the same as everyone else
- Worries about their future care
- Worries about your own care when you as parents are older as your child's spouse could look after you
- Worries about their sexual behaviour
- Feeling that marriage is the only way of keeping them safe
- A sense of family duty and honour
- A belief that the religion means that a person must marry and that marriage is God's will.

Feelings within the family

Thinking about your son or daughter's capacity to consent means thinking about their disability and this is understandably painful.

If it becomes clear that the person does not have capacity to consent to marriage and they cannot legally get married, or have a sexual relationship, then this can feel shocking and sad.

Parents and the whole family can feel grief like the grief they felt when they were told their child had a learning disability.

There may feel a lot of anger within the family, towards others and professionals.

Both you and your family may fear rejection by the community because of feeling different

Feelings about professionals

Parents and families of someone with a learning disability can find it hard to understand when professionals get concerned about family wishes for their son or daughter to get married.

They can feel that professionals are interfering with family life and forcing their view on the family.

They can feel that professionals are preventing them finding a way forward for the future of the family and for their son or daughter.

They can feel that they are being judged as not good as parents. This can feel hard as parents want to hear they are doing "a good job".

4. Faith leaders and marriage

Faith leaders of all religions agree that marriage without consent is unjust and oppressive and that marriage without consent is not God's will.

A faith leader must talk with you about capacity to consent when discussing the marriage of an individual who has a learning disability.

A faith leader would not be able to change the law for your son or daughter.



5. Protecting people at risk of harm

Parents are usually very aware that their son or daughter is more vulnerable and at more risk of harm than most people. It is important to know about the laws that are in place to protect people wherever they are living.

Someone with a learning disability will not understand as well as other people about the risks of living an adult life. Someone with a learning disability is more at risk of all forms of abuse including sexual abuse, physical abuse and financial abuse. What it means to you for your son or daughter to be safe and protected from harm will be linked to your own experiences and beliefs. It is important to share this with those who support you.

Why do we need to look at mental capacity about marriage when a person has a learning disability?

- Mental Capacity is about being able to make a specific decision for ourselves in relation to any area of living at the time when the decision needs to be made it is i.e. legally defined in the Mental Capacity Act 2005 and came into force in 2007.
- The Mental Capacity Act aims to keep adults safe and also value their independence.
- Professionals will have to take safeguarding action if a marriage is being planned or has taken place for someone who has a learning disability and who is unlikely to have capacity to consent to this. These actions are to keep them safe.
- The legal definition says that if someone cannot do one or more of these four things concerning making a decision about a particular matter then they lack capacity. The four things are understanding, retaining (remembering at the time), and weighing up the information, and communicating the decision.
- It has to be clear that they cannot do these things because their mind or brain is affected.
- The Mental Capacity Act does not allow anyone to decide that another person can get married or have children if they cannot decide this for themselves.

There are useful resources about the Mental Capacity Act for families and friends of people with learning disabilities on the internet and here is a link <http://www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act/>

Roshanara is 26 years old and has a learning disability. She has been on holiday abroad with her family. She tells her friends and support staff that she is now married. She is very pleased about this. Staff are not sure she understands enough about marriage and having a sexual relationship so they contact the social worker. The social worker knows Roshanara and her family well. The social worker thinks that she may have capacity to consent and talks with Roshanara and her family. All agree that a capacity assessment will help Roshanara's situation become clearer. She agrees she will not have contact with her husband until this is done. The assessment shows that Roshanara does have capacity. Following this she visits her husband again.

When a person does not have capacity to consent to marriage and a sexual relationship

When someone does not have capacity to decide to get married and have a sexual relationship they cannot consent to marriage and a sexual relationship.

Marriage cannot be the legal way forward to help them develop their life and be looked after. In this situation any marriage will be against the law. The Court says that capacity to consent to marriage and sexual relationships is about all marriages and sexual relationships for that person at that time.

The person would not be able to protect themselves from any abuse, unhappiness or harm that might happen because they are married. The person is likely to suffer trauma by being in a relationship and a sexual relationship that they cannot understand.

If a person does not have capacity to consent to sexual relationships then if someone has a sexual relationship with them they are committing a sexual offence.

Raj is a 24 year old man with a learning disability. He has an illness that means he is finding it harder to function in all areas. When he was younger his parents spoke with him about getting married but they can now see he is more disabled and would not be able to understand and consent to this. Raj's parents feel very sad about their son's illness but decide that they will be with him in a positive way and help him have enjoyment every day.

Forced Marriage

You may ask why do professionals talk about Forced Marriage when I am thinking about marriage for my son or daughter with a learning disability?

There are other important laws as well as the Mental Capacity Act. **The Forced Marriage (Civil Protection Act) 2007**, the **Anti-Social Behaviour, Crime and Policing Act 2014** which made forced marriage illegal, and the **Sexual Offences Act 2003**.

It has been agreed that a Forced Marriage is a marriage without consent of one or both people and where duress (pressure of any kind) is a factor. The law states that duress does not have to be a factor for a marriage to be forced when a person has a learning disability and does not have capacity to consent. This is even when the person says they want to marry, or if the family believe the person is happy about it, or if they believe they are doing the right thing.

When a person with a learning disability does not have capacity to consent to marriage and then they go through a marriage this is viewed in law as a Forced Marriage.

If someone with a learning disability has capacity to consent to marriage they can still be a victim of a forced marriage if they are put under pressure or tricked to marry.

Consent can only be legally given when the person has the appropriate information so a person who marries someone with a learning disability may be judged as being in a forced marriage if they have not been told that their spouse has a learning disability.

Forced Marriage forced marriage is against United Kingdom law as well as being against the values and rules of all religions.

The Court of Protection

Sometimes after assessments and discussion there are still disagreements and different views between families and professionals. When this happens local authorities or health trusts will make an application to **The Court of Protection**.

The Court of Protection can decide whether a person has capacity to make a particular decision for themselves and can make declarations,

decisions or orders on welfare matters affecting people who lack capacity. The professionals that are involved with assessing and supporting your son or daughter will be involved in reporting to the court.

When there are disagreements it is the court that will decide whether the assessment is accepted and whether the person does or does not have capacity.

Attendance at court and support

In most cases parents will be invited to attend the court and usually they will have their own legal representation although they will probably have to pay for this. The person with an intellectual disability will always have their own legal representation and will sometimes attend court in person.

The Mental Capacity Act has created an **Independent Mental Capacity Advocate (IMCA)** service for people who have no family or friends that can be consulted for serious decisions or for situations that need adult safeguarding even though there are family and friends. An IMCA will meet with the person with a learning disability to gain their view and will report to court.

If parents go against the decision of the court

When the court decides that a person does not have capacity to marry then they will explain to you as parents and family what may happen if you go against the decisions of the court and are involved in any way with the person getting married.

The Forced Marriage Act can be used to:

1. Remove the person from their home to a place of safety.
2. Impose fines.
3. A prison sentence in some circumstances the court can order that our son or daughter's passport is given to the Local Authority.

Gerald is 40 years old and has a learning disability. He needs support in most areas of living. He tells staff at the day centre that his cousin wants to stay in this country and they are getting married this weekend. Gerald says that his Mum told him to do this and he keeps repeating "okay". Staff are worried as they do not think he has capacity to consent.

Staff contact the community learning disability team who come and speak with Gerald that day and carry out a capacity assessment. This shows that he does not understand what a marriage is and that the decision for him to marry is not his own. To keep Gerald safe the local authority social worker goes to court and gets a court order. This order means that Gerald is taken to live in a specialist placement away from his family. At the moment the family do not have the address.

6. Who can I talk to about how can I get help to look at mental capacity about marriage when my son or daughter has a learning disability?

When is it best to ask for help?

Begin to talk with professionals who know your son or daughter when your child is young.

You can talk with the GP, specialist health professionals working in child development and with school staff.

You can talk about all issues to do with your son or daughter's present and future needs.

Parents and the young person will have a chance to talk about views and aspirations within the Education Health and Care (EHC) Plan at the EHC planning meetings and teachers and professionals will discuss these with you. This will include when you say that you hope your child will get married in the future.

As your child grows up, schools and colleges and centres for daytime activities can be very important in helping your son or daughter learn about safe and positive relationships, including sexual relationships.

The kind of services and support offered to your son and daughter when they have left school will be different from when they were younger. The professionals that you know as a family will end their work and new professionals will work with your son or daughter. This can feel worrying and as if the family is left on its own to cope.

When your son or daughter becomes an adult they continue to have the right to have assessments and support.

Some families and people with learning disabilities find it helpful to get spiritual guidance and emotional support from faith leaders and people at places of worship.

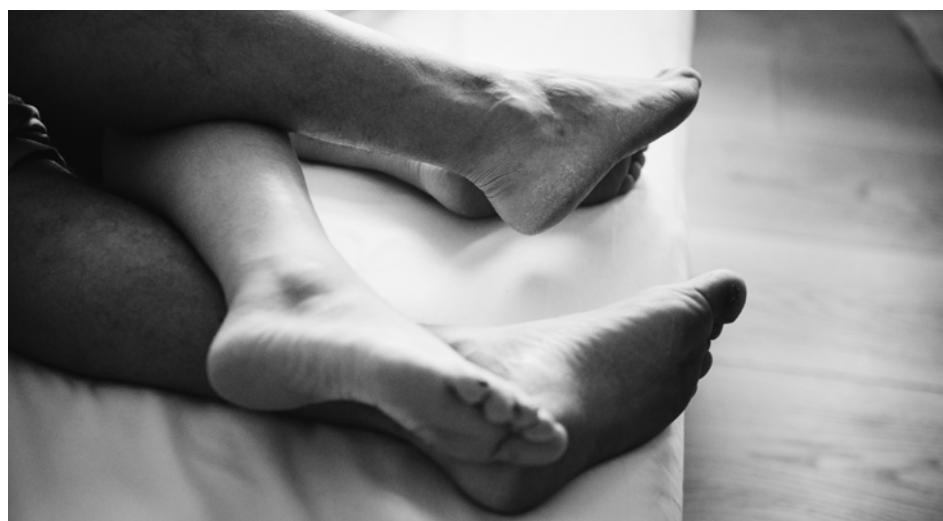
Talking with professionals about capacity as your son or daughter gets older

Over time you will develop a view about whether or not your son or daughter has enough understanding of marriage and sexual relationships to have capacity to consent. Other people who know them will also have a view.

It is a good idea to have discussions about capacity with health professionals, including the GP. You and your son or daughter can get specialist support, advice and help from health professionals in your local community learning disability team and from specialist social workers in your local social services.

If you are planning a marriage for your son or daughter then it is advised that you definitely have these discussions with professionals. Your son or daughter always needs to be involved in these discussions.

Even when the person with a learning disability has capacity to consent to marriage it is likely that they will need some specialist support. They will have to cope with new situations in their life. These services can usually carry out specialised sex education and work concerning having good relationships or can arrange for other services to do this.



Sex education

This is very important and will help your son or daughter understand and learn about:

- Sexual feelings and sexual attraction
- The sex act
- Sexual health
- Pregnancy and contraception
- The importance of consent to sex and the right to choose whether or not to have sex.

Sex education needs to be sensitive to the person's cultural and religious background and their particular emotional and learning needs.

Sex education as the person grows up may be important in helping them to develop capacity. This learning will also be part of helping them to be safe.

Harbinder is a 19 year old man with a learning disability. His parents have begun to think about arranging a marriage for him. Harbinder says he wants to marry. They know about the law and want to be confident that Harbinder understands what it means to get married and have a safe sexual relationship. Therefore the parents contact the local community learning disability team and ask them for a meeting. Professionals agree with Harbinder and his parents that specialist sex education would be helpful for him. He also needs help to develop his independent living skills. Harbinder's parents tell him that he is much loved and valued by his family. They talk with him about arranging a marriage when he can understand this and say they will not start looking for a wife until this time.

7. Mental Capacity Assessment

Mental Capacity Assessment: Good Practise

Family or professionals who support someone with a learning disability can ask for a Mental Capacity Assessment to be done. This will usually happen if there is a "reasonable belief" that the person does not have capacity, at the present time, to make a decision about specific and important matters in their life. The assessment is usually done by a specialist social worker in your local social services, or by a clinical psychologist or psychiatrist in the local community learning disability team.

The professional who undertakes the capacity assessment will have had both training and experience in this area.

They will write a clear report with all details of the assessment. They will show how they carried out the assessment. They will write their conclusions and professional opinion about the person's capacity. Other specialist health professionals such as a speech and language therapist, occupational therapist and community nurse may do some assessments as part of the capacity assessment.

Usually professionals will talk with the parents and family and other carers to gain views and explain the findings of the assessment. Occasionally the professionals may not talk with anyone else, e.g. if this would put the person at risk.

While the assessment is being done both the person with a learning disability and their family can feel anxious. It can be helpful to discuss your anxieties with professionals and with other people who support you.

How the Mental Capacity Assessment is done

The professional doing the assessment will want to know how it was agreed that the person has a learning disability. They will want to know about the person's development from a young age. They will want to know about the person's cognitive abilities, daily skills, support needs and about their communication skills.

"All practicable steps" will be taken to give the person a chance to show they have capacity.

Different sorts of questions will be asked in different ways according to the person's individual abilities and needs and their cultural and ethnic background.

Therefore there is no one set of assessment questions and it would be very difficult for the person with a learning disability to learn the answers in advance.

The assessor will often use culturally-specific pictures and interview schedules about marriage and sexual relationships, for instance questions based on the Islamic marriage contract or general marriage contract.

Communication is very important and where needed there will be an interpreter, or the use of Makaton Sign Language. The assessment may take place over several sessions.

Assessing capacity to consent to marriage

The person will be asked about many issues to do with their understanding and expectations of marriage. It is particularly important that they are aware that they have a right to choose to get married and a right to refuse to get married.

Examples of questions about this may include:

- Why do people get married to each other? The person may be given responses to choose from, e.g. love, because parents tell them too, to have sex, to have children or to receive presents.
- Where would your wife/husband live when you get married?
- Where would your wife or husband's clothes and shoes go?
- What things would you like your wife/husband to do for you?
- What happens if she/he did not do any of these things?
- Can you change your mind if you get married?

Assessing capacity to consent to sexual relationships

The court has agreed that to have capacity to consent to sex a person has to have a basic understanding of these such as:

- What is the sexual act (the mechanics of the sexual act).
- That there are health risks involved (the risk of pregnancy or of sexual transmitted diseases or of emotional harm).
- The right to choose to have or refuse to have sex.

Examples of questions about this may include:

- What do you understand when people talk about "having sex"?
- What can happen because you have sex?
- How does a woman become pregnant?
- Where does a baby grow and what happens at the end of pregnancy?
- If a man and a woman do not want to have a baby when they have sex what can they do?
- If someone wants to have sex with you do you have to do this?

The person may be shown some specialist drawings of sexual images in order to help assess their understanding. These pictures are carefully drawn to sensitively show sexual activity between adults and try to avoid offence. The person's response can be very helpful to the assessment.

8. When someone does not have capacity to consent to marriage

What will professionals do when the assessment shows your son or daughter does not have mental capacity to marry?

A social worker will be involved and will meet with you.

The professionals who know your son or daughter will want you to understand the findings of the assessment and accept this.

They will work together with you to give support to you as parents and as a family. They will give support to the person with a learning disability, particularly around the help they need now and future planning.

Sometimes the parents and family or the person with a learning disability find it hard to accept the assessment outcome.

When there are concerns about vulnerability, protection and safety the professionals will want to take further action to safeguard the person with a learning disability.

Coping after an assessment shows your son or daughter does not have capacity

Finding out that your son or daughter does not have capacity to consent to marriage and sexual relationships can be a big shock. You may feel for a while that this is "heart-breaking" both for you and your son or daughter.

You may feel anxiety, sadness, loss and anger. You may again have worries about future care and other matters.

Care and support for the person with a learning disability and their family becomes even more important than it was before. However finding out about capacity can also be a good opportunity. Everyone will be clearer about recognising the needs of your son or daughter.



Over time this can be helpful in thinking about how the person can develop new things in their life in a way that keeps them safe and can help planning for these things. This may include thinking about new services and supported living and accommodation in the longer term.

Coping with feeling different as a family

Finding out that your son or daughter does not have capacity to consent to marriage and sexual relationships means thinking about their disability and what this means for them and your whole family. Sometimes families find it hard to come to terms with this. A family may feel marked as different and have a sense of stigma about living with disability. This can affect relationships in the family and in the wider community.

You may feel isolated and distressed and it is really important to get support from professionals, friends, faith leaders and people in religious centres.

Sometimes you may feel angry with professionals who have been involved in the mental capacity assessment and taken actions to safeguard your son or daughter. This can leave you finding it hard to trust them again.

This is understandable and it is important to talk about these feelings. You can ask to talk with other professionals in the team or professionals in a different service who have not been involved with the assessment.

Adanna is 35 year old woman with a learning disability and her mother recently died. Her father said that it would be best for her to marry an older man who is a family friend. Adanna said she wanted to get married and have a lovely party and nice things to eat. Professionals who knew Adanna had serious concerns about her capacity to consent.

They carried out a capacity assessment and got more information about the family's views. Adanna was found not to have capacity to consent to marriage and sexual relations. Her father agreed to call off the marriage but was very distressed and angry. To begin with Adanna was upset that the marriage was not going to happen. With support from her day service she became calmer.

Many of her father's concerns were to do with who would care for Adanna now and what would happen to Adanna in future. Adanna was offered some daily support with personal care from female support workers. Over time health and social care professionals from the local community learning disability team worked with Adanna and her father about her moving into local supported living and extending her regular activities.

Not refusing help and building up trust about services is very important

After the assessment that shows that someone with a learning disability does not have capacity to consent to marry there is a lot of work to do in a partnership between services, the person with a learning disability, and their parents and family.

You may be worried about how you will cope with your son or daughter's reaction to not getting married or to their marriage ending.

Your son or daughter may feel sadness, loss and anger. It may be difficult for them to tell people about these and they may express these emotions through behaviour that challenges, such as getting angry at others in the family or refusing to do things.

This is the time to ask for support and help from others. The person with a learning disability and their parents and family may get help from talking with a social worker or seeing a psychologist or a psychotherapist. You can

ask your GP or your local community learning disability team what help is available.

9. Getting support

Many families and people with learning disabilities need support about how they feel and in thinking about these things. Support can be gained from:

- Friends and relatives
- Faith leaders
- Staff in schools and colleges
- Staff in day and support services
- Health professionals including the GP
- Professionals in Community Learning Disability Teams
- Social workers
- Charities and community organisations.

Living well without marriage

When the person with a learning disability does not have capacity to consent to marriage it is important to help them to have good and happy relationships without marriage.

They will need support to find positive and meaningful activities so that they feel they are a valued member of their family and community.

Parents and family are really important and being positive about difference and lessening stigma will help the person with a learning disability to build a satisfying life without marriage. Staff who support the person also have a very important role.

It is important for your son or daughter, your family and the community to develop alternative adult milestones.

Together you and your family can create celebrations of life for instance about being valued family members or about their relationships and about their achievements in developing new skills.

Brian and Sofia have lived together in a staffed house for 15 years since their early twenties. They are both severely disabled and wheelchairs users. They communicate by facial expressions and gestures. They spend a lot of time looking at each other and smiling. Recently Sofia went into hospital for a routine operation. At this time Brian became very upset and refused to eat. He was very pleased to see Sofia again and she smiled a lot and held her arms out to him. Staff moved Sofia closer to Brian and they hugged. Staff now realise that Brian and Sofia have a strong attachment to each other and that they love each other. Staff have talked with both Brian and Sofia's elderly parents and together they have thought about how to support Brian and Sofia in loving each other. Staff now offer the couple meals together and shared activities. Every year they have an anniversary celebration on the day that Sofia moved into the house.

Sofia and Brian do not share a bedroom but staff leave them together to have some private time to hug. Staff have agreed to communicate to both Brian and Sofia about any future separations.

Supporting the person with their sexual needs

Men and women with learning disabilities who do not have capacity to consent to marriage and sexual relationships still have sexual needs. It is important that they develop their sexuality and sexual expression in ways that are safe for themselves and other people.

Sometimes there is a strong belief that sexual expression is only acceptable within marriage. This can feel a very difficult and taboo area for parents and families to think about.

Being unable to marry due to lack of capacity can be a big challenge to your son or daughter and the family especially how they will meet their sexual needs. Getting support from skilled professionals can help deal with these challenges and help you support your son or daughter. Sometimes expressing sexual needs can be seen as being in conflict with religious beliefs and talking through concerns with faith leaders can lessen these anxieties.

Getting support can help you cope with embarrassment you may feel talking to your son or daughter about their sexual feelings and what they understand about having a sexual relationship.

Akhtar is a 25 year old man with a learning disability who needs a lot of support in all areas of daily living. He says his parents and sister say "get married". Assessment shows he does not have capacity to consent to marry at the present time. Support workers are aware that he gets sexually aroused and Akhtar calls this "feeling bad". He has angry outbursts and has tried to hug a woman at college. Support workers think this is to do with sexual frustration. Professionals work with the family and Akhtar about their understanding and acceptance of his sexual needs. A plan is developed involving his male support workers. His father also speaks with his faith leader who reassures him that this plan is permitted. Workers support him to go to a private place to masturbate and wait outside until he is ready. Workers also help him learn about appropriate touch and positive relationships.

People who have capacity still need support

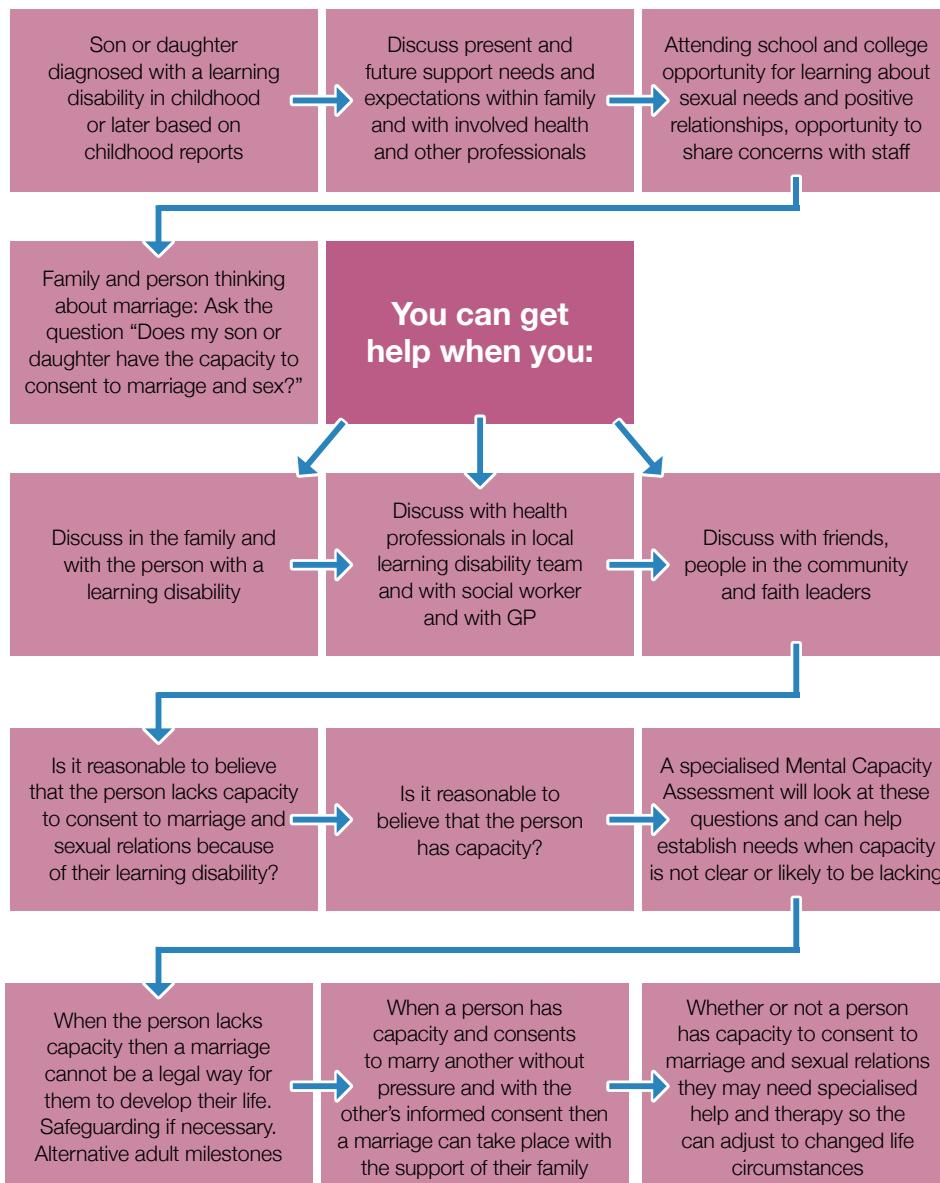
Many people with a learning disability will have capacity to consent to marriage. These people will benefit from the positive support of their family in finding a marriage partner that they choose to marry and in developing a strong and loving bond.

A person with a learning disability who gets married may need specialist support in preparing for and coping with marriage and possible parenthood.

They will often need help to cope with changes in living circumstances. A community learning disability team can offer specialist help or signpost the person to other community services that can do this.

Hannah is a 31 year old woman with a learning disability and autism. She has developed a range of independent living skills. Hannah has an affectionate relationship with a young man with a disability who is part of her local community and they both say they want to marry. Both Hannah and her boyfriend are assessed as having capacity to consent to marriage and sexual relationships. With the support of their families they get married. Hannah and her husband need specialist support to understand how to use contraception as they say they do not want to have a baby at the moment. Hannah and her husband also ask for some help in learning how to cook, organise their flat and manage their money.

Thinking about capacity to consent to marriage and sexual relationships and how to get help and support



How to find out more information and advice

Community Learning Disability Teams/Services are in all local areas. You can ask your GP or Local Council about contact details and a referral or you can find out more on the internet.

You can ring **Respond** to speak to the My Life, My Marriage Project Lead or on **020 7383 0700** and staff there can give you ideas about where to find support in your local area. Or visit www.respond.org.uk for more information.

Forced Marriage Unit contact details:

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