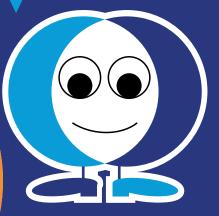


**Closing The Gaps** 

for all those with learning disability & mental ill-health

# Inclusion in the Jewish Community An Interactive Handbook

"Welcome everyone...with joy" (Pirkei Avot, 1:15)



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"Though it is not incumbent upon you to complete the work, nor are you free to desist from it entirely" Rabbi Tarfon, Ethics of the Fathers 2:16

### The Inclusion Campaign



Judith is a lady who lunches. She likes going to galleries, to the theatre and exploring country houses. She enjoys shopping, holidays and being with her family. Judith is a much-loved sister, aunt and friend. Judith is a Jewish woman who enjoys celebrating Shabbat and festivals, and loves Jewish food. Judith has learning disabilities and mental health problems.

Judith spent much of her adult life in care institutions, with little contact with the Jewish world. Now she lives in a Jewish home and thrives on participating in the rituals and rhythms of Jewish life. Our research shows that other people with learning disabilities and mental health problems also value their Jewish identity and want more opportunities to learn about and participate in Jewish life.

The Judith Trust Inclusion Campaign works to ensure that people with learning disabilities and/or mental health problems are able to be involved in the Jewish community in whatever way they choose.

### Who is this book for?

This book is for all community members. Whether you are a professional, a lay leader or a member interested in inclusion, there is something here for you.

### How to use this book

The book contains short activities, information and case studies. All the activities are short and self-contained, and you can do them in any order, though it might help to work through in order. There are also tips from communities where we have worked.

Share the book around your community. At the end of the book is an Action Plan which you can each copy, complete and follow-through, to promote inclusion. Please contact the Judith Trust if you would like further information or support.

You can also participate in our e-learning programme, which contains similar information and activities, and is continuously updated, at **www.judithtrust.org.uk/e-learning**.



Copy this quiz and use it as a trigger to inclusion activities and discussions.

Tip

Answe	ers
1	False – Widening the opportunities and interactions available to people with learning disabilities can vastly improve their quality of life.
2	<b>True</b> – Eating disorders are a way of coping with feelings that are making a person unhappy or depressed. It may be difficult to face up to, and talk about, feelings like anger, sadness, guilt, loss or fear, or a lack of control in their life. An eating disorder is a sign that someone needs help in coping with life, and resolving personal problems.
3	False – People with Down's Syndrome experience the same range of emotions, feelings, behaviours and personality traits as anyone else.
4	False – It is true that everyone feels down sometimes, but for some people this is deeper and more prolonged; it starts to affect how they function on a day-to-day basis. As well as medical interventions, receiving practical, social and emotional support can be an important part of recovery from depression.
5	<b>True</b> – Some mental health conditions are more common in women and others in men. Depression and anxiety are 1.5 - 2 times more likely to occur in women, and 90% of those with eating disorders are women. Personality disorders, schizophrenia, substance misuse and post-traumatic stress disorder are more common in men.
6	False – People with mental health problems are much more likely to be the victim of such a crime, than to commit it. They are also more likely to harm themselves than others.
7	False – A small proportion of people with autism have 'savant' skills but most people with autism have a range of things they are good at and things they are less good at, much like everyone else. Up to 70% of people with autism also have learning disabilities.
8	False – It is important to develop religious and cultural identity in children with learning disabilities. The key is to find out what helps them to learn in English / secular studies and to utilise these tools in Hebrew / Jewish studies.
9	False – Traditionally Judaism exempts many with disabilities from certain obligations, including that of praying three times a day. However sources show much discussion and disagreement, and often an effort to be as lenient as possible. There has been a considerable change over recent years, with new understanding in both the Jewish and secular world as to what it means to have a learning disability, and the different possibilities made available for expanding the 'learning experience' of many who might in earlier times have been ignored. Every effort should be made to teach those with learning disabilities in accordance with the way in which they can understand, and to allow them to participate in every aspect of synagogue life as much as possible.
10	<b>True</b> – Being part of a caring community promotes and protects mental health, and prayer and religious ritual may also be helpful.

# 

### What's it all about?

There are many myths and misconceptions around learning disabilities and mental illhealth. Here is some basic information:

### What is a learning disability?

#### 1. What is a learning disability?

A learning disability is a life-long condition; with support people can lead productive and fulfilling lives. A learning disability, or 'developmental delay', affects a person's day-to-day living, communication, social and behavioural skills. It does not mean a person cannot learn or develop, but that this may take more time, support and creativity.

#### 2. How many people have learning disabilities?

There are about 1.5 million people in the UK with learning disabilities. About 5,500 of them are Jewish.

#### 3. What types of learning disabilities are there?

There are many conditions associated with learning disabilities, such as Down's Syndrome, autism and global, or developmental, learning delay. It may help you to understand the individual if you find out about their condition. However, each person with a learning disability is an individual; getting to know them is more important than knowing about their condition.

#### 4. What support will someone with a learning disability need?

Focus on what people CAN do for themselves, or with a small amount of support; many can travel, work and make friends. People with complex, or higher support needs may need help with every aspect of their life, including personal care. Each person with a learning disability is an individual with different strengths and needs.

#### 5. Why do people with mental health problems sometimes react in ways we find difficult?

This is referred to as 'challenging behaviour'. When people are mentally distressed, upset, or struggling to communicate, their behaviour can be unpredictable. They may become angry, hostile, behave in socially unacceptable ways or withdraw. Getting things right for people can prevent them from getting distressed, so it is important to get to know them and their personal preferences.

Tip

Ask your Rabbi to give a sermon, so the wider community can hear about why inclusion matters and how you can make it happen.

### What is Mental III-Health?

In this section, we use the terms mental illness, mental ill-health and mental health problem, interchangeably.

#### 1. What is a mental health problem?

Mental illness can affect the way a person thinks, feels and behaves. It can affect relationships, work, day-to-day functioning and quality of life. Many people with mental illness experience stigma, prejudice and discrimination. With support, many people with mental health problems can lead full and productive lives. The impact of a mental illness can also affect family and friends.

#### 2. How many people have mental health problems?

1 in 4 people experience mental ill-health within their lifetime.

1 in 10 under 15's has a diagnosable mental health problem.

Up to 4 in 10 people with learning disabilities experience mental ill-health.

#### 3. What types of mental illnesses are there?

There are many types of mental illness, such as depression, schizophrenia and anxiety. It may help you to understand the individual if you find out about their condition. However, each person with a mental health problem is an individual; getting to know them is more important than knowing about their condition.

#### 4. What can help a person with mental ill-health?

Medical treatment is effective for some people. Talking or creative therapies may also be helpful. Friendship, support and inclusion are central to improving mental well-being. Research also shows that religion, spirituality and culture can promote mental well-being.

# 5. Why do people with mental health problems sometimes behave in socially unacceptable ways or withdraw?

This is referred to as 'challenging behaviour'. When people are mentally distressed, upset, or struggling to communicate, their behaviour can be unpredictable. They may become angry, hostile, behave in socially unacceptable ways or withdraw. Getting things right for people can prevent them from getting distressed, so it is important to get to know them and their personal preferences.

#### 6. Why do people with learning disabilities experience an increased likelihood of mental illness?

People with learning disabilities experience higher rates of physical health problems, high unemployment, fewer relationships and often have less control over their own lives. These all contribute to increasing the chances of experiencing mental ill-health. Increasing spiritual, cultural, social and work opportunities can reduce the chances of mental ill-health occurring.

### Language

Language influences how we think, feel and behave towards people. It is therefore essential to consider the language we use in relation to people with learning disabilities and mental health problems.

• Think about these everyday terms we all might use; understand that these can be seen as offensive and disabling to people, and how we can speak in a more appropriate way

#### He is handicapped

The term 'handicapped' is no longer used in the UK – it originates from the image of people going 'cap in hand' to beg, which is obviously an inappropriate image for people with disabilities today. It has been replaced by 'disabled', which is widely used by most people.

#### She is confined to a wheelchair

She is a wheelchair user, or a person who uses a wheelchair; 'confined' or 'wheelchair bound' emphasises the limitations on the person, rather than their abilities.

#### She is a bit crazy

She has a mental illness, mental ill-health or a mental health problem, are all commonly used terms. We often use terms related to mental illness, such as 'crazy', 'loony' or 'nutter', in a derogatory way and this should be avoided.

#### He is deaf and dumb

'Hearing impairment' is more often used now, although many deaf people still use the term 'deaf'. The term 'dumb' is no longer used; someone who does not speak is referred to as 'a non-verbal person'.

#### She lashes out and is really difficult

The term 'challenging behaviour' is used to describe behaviour which puts people at risk, or leads to exclusion, for example from school, social groups or community facilities. This emphasises that it is behaviour which others find challenging and need to understand, rather than placing the problem within the person.

### "We are people first, our disability is second"

Use the term 'person with a disability'. Similarly for other conditions e.g. 'a person with epilepsy' or a 'person with diabetes', not 'an epileptic' or 'a diabetic'

When getting to know someone, do not focus on the 'label' the person has, but get to know the person, as an individual. Ask the same questions you would ask of anyone you meet for the first time – holidays, work, home life, music preferences, TV shows they watch and so on.

## What is Inclusion?

"An individual is socially excluded if he or she does not participate in key activities of the society in which he or she lives" (Royal College of Psychiatrists, 2009).

The aim of the Judith Trust Inclusion Campaign is that everyone should be able to access and enjoy the benefits of being part of the Jewish community. The rest of this handbook explores barriers to this and how they can be overcome.

### Here are some examples of the achievements of the Inclusion Campaign



Members of Langdon's Brady Club achieved their Yoni Jesner Volunteering Award



Inclusive Rock Group, The Autistix, performed at Harrow Day Limmund



About 60 people participated in an interactive event at the Jewish Museum

"The volunteers at the shul made me feel safe. It was good to have a friendly face when we first went" (A couple with learning disabilities who have joined a shul) "A 16 year old girl came with her parents and then went and joined a youth group" (Shul volunteer who arranged an inclusion event)

"The meeting was structured, organised and informative – now we know how to move forwards with this" (Participant in a shul information session)

# What do you get out of being part of the Jewish Community?

Reflect for a few moments on what you get out of being part of the Jewish Community

#### Here are some answers people have given in our sessions:

- Friends
- Support
- Learning opportunities
- I find it powerful praying as a community
- A job
- A structure and purpose to my life
- A great life for my children
- Holidays
- A world of culture art, music, films, humour

Now see what people with learning disabilities and/or mental health problems, who go to shul regularly, have said in response to this question:



### **Gregory's Story**

My name is Gregory. I live in a group house with some support from staff. I go to a Norwood group called the 'Jewish Way of Life' where I learn lots of different things. I also like going to the Jewish Care centre.



My shul is really near my house. I used to see people going to shul and I wanted to go too. I had help from staff at Norwood to meet the Rabbi and to start going to shul. We talked about what I should do in shul, like where to sit, not talking in the service and to introduce me to people.

Going to shul is an important part of my religion because I am Jewish. I have friends there now. I see them every Saturday. I really enjoy the service and the kiddush. I get called up to open the ark.

Last Pesach I went to a community Seder and I read a prayer – I felt really proud of myself. I took another friend who lives with me, with me, because she is Jewish too and wanted to come.

I like reading the shul magazine because I am part of that. I was in the last magazine! I have been shopping to buy a talis to wear when I go to shul. When the Chief Rabbi came to my shul I met him, which was very exciting. I am really happy that I started going to shul.

### Could you support someone like Gregory to become part of your community?

Remember to add to your Action Plan



Tip

Ask people with learning disabilities and/or mental health problems in your community to be involved in your inclusion work; they are your best champions!

# **Benefits of Inclusion**

### Research shows that spirituality helps to protect a person's mental health through:

- Religious practices such as prayer and reading religious texts
- Joining a caring community and living by certain values
- Wearing particular clothes or eating special foods
- Cultural or creative activities, writing poetry, making music, creating art, getting closer to nature
- Activities that develop self-awareness or personal control such as meditation, Yoga or physical activity, friendship or voluntary work

Professor Martin Aaron (2011)

### Through having spirituality in their lives, individuals have gained:

- Improved self esteem and confidence
- Faster and easier recovery
- Better relationships with self, with others and with G-d, creation and nature
- A sense of meaning, hope and peace of mind

The Royal College of Psychiatrists (2009)

# The Judith Trust Inclusion Campaign stems from research we commissioned with adults with learning disabilities, which showed:

- Being Jewish was important to people; it provided a sense of strength, social belonging and inclusion, and was part of their personal identity
- Judaism offers valued rituals, traditions and roles for some people with learning disabilities, such as saying prayers on Shabbat, attending synagogue and being called to the bimah
- Participation in the celebration of festivals was highly valued. Singing, dancing, music and parties were important to people
- Attending Bar and Bat Mitzvahs and weddings was important to many participants
- Religious observance was seen by many as a sign of respect for the Jewish faith
- A significant number of people wanted more opportunities for religious and spiritual education and development
- A significant number of people were interested in culture and skill development, such as Jewish cooking classes, discussion of Jewish culture and reminiscence

Eve Hersov (2007)

## **Barriers to Inclusion**

The Social Model of Disability highlights barriers to inclusion and opportunity in three areas:

**1. The Environment** – inaccessible buildings, small spaces, fixed seating, poor signage, lots of written information.



**2. Attitudes** – stereotyping, prejudice and discrimination create exclusion and lead people to feel unwelcome or unable to access opportunities.



**3. Organisations** – inflexible or inappropriate practices, policies and procedures which result in exclusion.



Think about your shul and what you could do to help make people feel welcome.
 Try to come up with at least 1 idea related to the environment, attitudes and organisations.

Tip

A statement about inclusion on your website will explain your positive and proactive approach and encourage people to get in touch. It can be helpful to have a direct contact who has some knowledge or experience of learning disability and/or mental health, who will respond appropriately when people get in touch.

### How to be more inclusive

Now think about why people with learning disabilities and/or mental health problems might not go to shul.



Someone showed me round before I started going, so I knew what to expect when I got there – it was helpful to have time to look around when it was quiet and there were no people there

I wasn't sure which door to go into for the service and I couldn't find the toilets

Sometimes people stare and tut – it makes me more stressed and isn't worth bothering with

It is expensive to be a member

Identify people in the community who can be 'buddies' to welcome people, sit with them, show them round and introduce them to people. Teenage buddies can take children with special needs to the Children Service; this allows parents to be in Shul and children to integrate.

Tip

"The difficulty for people with disabilities has two parts – living our ordinary, but difficult, lives, and changing structures, beliefs and attitudes that prevent us from living ordinarily" Nancy Lynn Eiesland, Barriers to Bridges, National Organisation on Disability (USA)

I need to get more confident and understand more – I would like to go to some lessons Sometimes I have no-one to sit with and feel lonely – it would be nice to have someone to sit with

It would be good if someone called out the page numbers so I know where we are – they do this on festivals but not on Shabbat

There is not enough in English – I have no idea what is going on

Be friendly to my support worker too, because they are not Jewish and don't know about shul

> We didn't know there were things happening at the shul during the week – I would like to do some of those things and meet other people

> > Remember to add to your Action Plan



# Communication is about the whole person

Think about the possible barriers to effective communication.

Match the numbered body parts to the numbered circles to find out more about how it affects communication.



It is important to listen carefully and respond to people, even when it may be hard to fully understand them.

### A lack of eye contact can make it difficult to communicate. Some people with autism, however, find eye contact difficult and prefer to avoid it.

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Memory problems can affect communication. It might be helpful to repeat things, to write things down or to limit how much information you give someone in one go.

It is important to think about how you speak – consider using simple language, speaking slowly and clearly and your tone of voice. Accents can also affect communication. Touch can be a useful way of improving communication, for example a gentle tap on the shoulder to get someone's attention, or an arm round the shoulder to comfort someone. However, some people prefer not to be touched at all. Get to know the individual's preferences.

There are resources on The Judith Trust website, including Prayers in Makaton and picture formats which you can download - see 'Recources for communities'.

Tip

Difficulties with hearing can make communication harder. Be aware of positioning and face the person in case they lipread. Ensure equipment such as hearing aids and induction loops are working.

5)



Poor eye sight can make communication difficult. People with visual impairment may rely more on their other senses. Get to know the individual's preferences.

Feeling unwanted or unloved can discourage people from communicating. It can take time and effort to develop a relationship with someone so that they feel comfortable talking to you.

> Space is important when communicating, to be close enough without invading someone's personal space can be a difficult balance.

Some people may use Makaton, a simplified sign language, to communicate. Everyone uses gestures when communicating, and some people with autism find these hard to interpret.

### Environment

Look at this floorplan of a typical synagogue to find out how to make the environment more accessible.

### 2

All doorways should be wide enough to comfortably fit a wheelchair through, and without raised threshold between rooms. All doors should have signs with basic symbols, to help people orientate themselves when they first arrive. It should be clear, for example, where the toilets are, and where people are expected to sit during services. If activities take place upstairs, how accessible are they? If you have a women's gallery, is there seating for women downstairs during services? This is especially important if there is no lift, or the lift is not used on Shabbat.

5

There should be wheelchair accessible toilets available. It is important to have separate disabled toilets, for staff to support people of the opposite gender with personal care.

3

Synagogue office staff should have knowledge of how to help a caller with a learning disability. It may be helpful for the synagogue to have an 'easy access' contact via phone or email; communities have suggested a link on thier homepage, or a dedicated email address to facilitate this.

6

The 'Security check' sign might worry people, especially if it is the first thing they see on arrival.

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Security staff and volunteers should be aware that someone may have a learning disability or mental health problem, and may have a carer with them. They may not understand the need for security.

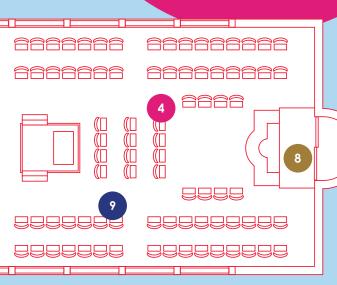
Security should be able to contact someone within the shul who can help the person if needed.

Do a tour of the Shul at a quiet time - it gives people a chance to orientate themselves and to see the bits they might not otherwise see, like inside the ark.

Tip

### "My house shall be a house of prayer for all" (Isiaih)

If there are allocated seats, someone needs to politely show a visitor where they can sit. A person might feel uncomfortable sitting very close to other people, especially if they do not know them. Some people with learning disabilities may also need personal space, for example a person with autism may rock, rather than sit still. It may be helpful to the person to sit at the end of a row, near the door, near a window, at the back or front, depending on individual needs, especially if the person may need to leave during the service. Ensure there is space for a wheelchair user to sit near other people, be able to converse with them, and to get in and out comfortably.



In communities where men and women sit separately, it is important to be aware that the person's support worker may not be of the same gender. In this case, both the person and the support worker would need someone to sit with and you would need to consider how you would get the support workers attention if there was a problem.

7

Steps up to the Bimah or Ark may prevent someone participating fully. Is there a ramp, or an option for them to participate on a 'ground level'? You may also need to allow extra time for someone to make their way to these areas.

8

It may be helpful for the person to sit at the end of a row, near a door, near a window, at the back or front, depending on individual needs, especially if the person may need to leave during the service

9

# Remember to add to your Action Plan



### **Accessible information**

You many not know of any people in your community who have learning disabilities or mental health problems. People with disabilities may be unaware of what is available in their community, and may also lack the confidence to try new things. Negative past experiences, and a belief that they are not wanted, nor able to participate, may stop people seeking out new opportunities. Outreach is therefore important in promoting inclusion.

### Compare these two flyers for the same event. Which is more accessible and why?



Tip

Copy the next page and give it to the people designing your flyers, posters, website, magazine and other information.

# **Distributing Information**

Feature	Avoid	Good Practice Guidance
Language	Very wordy	Use simple clear language, explain Hebrew words
Font	Varied sizes and colours, fancy font	Use a simple, clear font, bold colours and a minimum font size of 12; preferably more
Pictures	No pictures used	Include simple visual images, to describe the event Use a clear, consistent sign showing who to call if you want more information e.g.
Logistical Information Distribution	Time and cost given mid-sentence No finish time Booking only via the website Distribution only electronically, printed versions only onsite	Give key details in a format which stands out, such as a box Provide clear start and finish times, so people can arrange transport and support to travel if needed If you cannot print the address due to security, give a clear way for people to get the address Consider booking system for people who may not have internet access and/or debit cards Consider how information is distributed: On-site only; people who are not on the premises will not find out E-mail; do all members have access? Does not reach non- members? Post; does not reach non-members. If the mailing is large, people may miss key information The Judith Trust is able to provide synagogues with a list of local social care providers who can distribute information to interested people
Website	Wordy website, no images, small font, hard to find information	Websites should be designed to maximise accessibility, including easy-read sections, option to increase font-size and a facility to 'speak this section'

### **Distress and Challenging Behaviour**

Children and adults with learning disabilities or mental health problems may behave in ways which we find distressing or challenging. Behaviour is usually referred to as challenging if it puts the person or others at risk, or if it leads to exclusion from ordinary community facilities, like schools, synagogues or shops.

There are many reasons for this such as frustration, ineffective communication, boredom or unmet needs. People with mental health problems may be hearing voices, or experiencing hallucinations.

How do you respond to a person who is distressed or behaving in a way you find challenging?



Make eye contact to get the their attention. However some people with autism find eye contact difficult and prefer to avoid it.

Think about the person's level of understanding. Relate to them at their level. Remember, when we are distressed it is harder to process things, so keep information simple, and ask simple questions.

Think about their biological needs - could they be hungry, thirsty, tired, need the toilet, or be feeling unwell?

d

When a person is agitated use single words or short phrases. Say their name first to get their attention. Talk in a calm and gentle way; try not to raise your voice, even if they do.

Holding hands can help get a person's attention, and can be reassuring. However, some people prefer not to be touched at all. Get to know the individual's preferences.

Tip

Is there a quiet, private room where someone could go if they need some space?

It is important to listen carefully; ignoring comments, or behaviour, will usually only make it worse.



Reduce the amount going on in the environment, or take the person somewhere quieter. People with autism can be particularly distracted by too much visual stimulation.

Think about what could be causing the behaviour, and how you could calm the situation. Be rational and not emotional; don't take it personally.

If a person is struggling

with something it might

be useful to guide their

hand to help them.

Understand how the person might be feeling, rather than just focusing on what they are doing.

Think about how you are feeling – adrenaline may make your heart race and your body tense. Try to stay calm and breathe deeply; and encourage the other person to do so too.

Safety is paramount. It might be helpful to ask the person to leave the room, or if you cannot do this, to ask others to move away from them.

### **Boundaries**

- What if she asks for help going to the toilet?
- Is it OK to offer him a lift home?
- Can I invite her for Shabbat lunch at my home?
- He likes to hold my hand is that OK?
- She bought me an expensive gift should I accept it?

When a child or adult with learning disabilities/mental ill-health is being supported, there may be times when you are unsure about what is appropriate, or you are asked to cross usual social boundaries. This may leave both you and the individual receiving support feeling vulnerable or uncomfortable about what is happening.

Ideally you should agree what your role is at the outset. Talk to the individual and their carer, if they have one, about what support they need and want, and where it will take place. Consider how they will travel, how they communicate and what personal care needs they may have; there is a sample plan for recording this on our website. Avoid meeting in private places. People with higher support needs may come with a carer, but a volunteer within the community is still important – see 'Working with Carers' on p32.

If you are unsure what is expected of you, or you are uncomfortable with anything you have been asked to do, you should always speak to the individual, their family or carers, and seek advice from your Welfare Representative. You can also contact the Judith Trust for advice. Make a record of what the person said as soon as possible afterwards.

Tip

Tip: check your organisation's Safeguarding procedures regularly and update if necessary. Ensure all volunteers and staff understand them.

"The Haggadah refers to four sons: One wise, one wicked, one simple and one who does not know how to ask a question. We are taught to respond to each according to their needs."

### Disclosure



A person might say something to you which makes you concerned they are at risk. They could say that someone else is harming them or that they are considering harming, or have harmed, themselves.

Respond to the person by reassuring them, listening to them and saying you will try to get them some support. Ask them if there is anyone you can contact for them e.g. friend, family member, social worker, support worker. Do not promise confidentiality – explain you will only tell an appropriate person to get them some help.

Try not to ask too many questions, or to ask leading questions; listen and respond by repeating back and showing you understand and care.

You can help them to get support by signposting them to appropriate organisations (as listed at the back of this book) or by calling the organisations yourself. You should always tell the person if you are planning to refer them yourself, unless you feel this would put them, or yourself, at risk. Make a record of what the person said as soon as possible afterwards.

Always call 999 in an emergency. In non-emergency situations, call 101 (local police), 111 (NHS Direct) or use our contact list at the back of this book.

### Safeguarding

As a registered charity each Synagogue, or communal organisation, should have a Safeguarding Children Procedure in place. When working with vulnerable adults, if the person you are working to support is in receipt of social care services (e.g. residential or day care) you will need to work within their Safeguarding Policy; otherwise you may need to develop your own. Details on what should be included in a Safeguarding Policy include can be found on the Charity Commission Website

Best practice suggests that any volunteers/officers working with Children or Vulnerable Adults have a valid CRB check.

This information provided by the Judith Trust is advice only; the responsibility for ensuring Safeguarding of Children and Vulnerable Adults remains with the individual communities and institutions providing the support.

# **Children with Special Needs and their Families**

• Now consider how many children have special needs or mental health problems?

	In the UK (BBC News, 2011)	In a community with 300 children
Special Educational Needs (SEN)	21%	63
Statement of Educational need, entitling them to support	13%	39
Moderate learning disabilities	Approx 5%	15
Behavioural, emotional and social difficulties	Just under 5%	14
Autistic Spectrum Conditions	1.7%	5
Currently or have previously had mental health problems	10%	30

### • What opportunities do families with children have in a synagogue?

#### You might have noted things such as...

- A community baby-blessing
- A mother and toddler group
- A nursery

Tip

- Children's services
- Uniformed groups such as Brownies and Cubs
- Summer holiday schemes
- Religion school... And much more

# • Are these opportunities available to families with children with special needs?

Children with SEN have an IEP (Individual Education Plan) at school – why not have a JIEP (Jewish Individual Education Plan) at cheder?

### Remember to add to your Action Plan



26

### **Welcome to Holland**

Written by Emily Perl Kingsley



"I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to some horrible, disgusting, flithy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy a new guidebook. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever, go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland."

Having a child with a disability is not a chosen, clearly-mapped or easily-navigated journey. The Jewish community has immense specialist resources at this time of need; Jewish social care organisations can support families to deal with the challenges ahead. But this support should not be instead of, but in addition to, the support which local communities can provide.

### The Experience of Families

- Now read some statements from family members about their feelings and experiences within the Jewish Community.
- What makes a difference to families of children with special needs? What could you and your community do to make people feel welcome?



I left shul early one week; my child was being noisy and I felt everyone was looking at me. The Rabbi's wife rang me a few days later. We had a long chat. She told me everyone was welcome and that I should do whatever I felt comfortable with. The next time I went to shul, she came and sat next to me.

My brother wasn't welcome at the children's services. I felt angry about that. If they didn't want him, I wouldn't go either. We all stopped going to shul.

> I asked the cheder (Sunday school) teacher if there were any other kids like my daughter at the cheder. She said no. That was the end of the conversation. I didn't take it any further. But I desperately wanted her to say, "No...but we can see what we can work out for her".

Our shul has an 'anim zmirot' (prayer traditionally said by a child) group – they all get a special kippah when they have done it. The youth rabbi spoke to us about our son. We agreed he would try to learn the first line. He sang it loudly and clearly, and his brother sang the rest. He got his kippah and was so proud of himself.

My older son went to Cubs and loved it. One day, the leader asked me when my younger son, who has autism, would be old enough to start. I was so shocked – I had never even thought about sending him.

> I couldn't face going to the baby blessing ceremony. I had been to one before – wishing that your child should bring you only 'naches' (pride and good things) and grow up to stand under the 'chuppah' (wedding canopy). I knew that my child would not fulfil those blessings.

> > Remember to add to your Action Plan



### **Bar and Bat Mitzvah**

Although there is no requirement to commemorate a Bar or Bat Mitzvah in any way, for many, having one is an important rite of passage, and a celebration for the young person, their family and friends and the whole community.

Many young people with learning disabilities and/or mental health problems, and their families, experience challenges in planning a Bar/Bat Mitzvah which is meaningful and appropriate for them, and many young people with special needs do not have a Bar/ Bat Mitzvah.

Here Susan shares her experiences of organising a Bar Mitzvah for her son Saul, who has multiple and complex needs.



"Saul is 18 and loves music. Saul is very sociable and is a much loved member of his family and by all who know him. He swims, skis, horserides and loves going on holiday. Saul has been to the ballet, opera, theatre, music festivals, flamenco and the circus. Saul is definitely the hardest working and busiest member of our family!

I have worked tirelessly for Saul to have the same opportunities as his sisters and to be included in everything we do. I was determined to help him to achieve his Bar Mitzvah, just as his elder three sisters had had their Bat Mitzvahs before him.

From the youngest age, our Rabbi would point to Saul and say 'I'm going to Bar Mitzvah this boy'. When Saul was 10, I contacted our Rabbi, to start planning. I could not have been more astonished when he responded "I cannot help you". I felt shocked and betrayed, and overwhelmed with the burden of trying to work it all out myself. I was determined that Saul should have a Bar Mitzvah. I began to look outside our synagogue for a possible solution and discovered a huge gap in the Jewish community.

I visited an Israeli-based Bar/Bat mitzvah programme for children with special needs, which showed me examples of what had been done for other children and encouraged me in my quest to achieve something suitable for Saul. Saul's speech therapist told me about a young graduate in Speech and Language Therapy who was also a Chazan at a nearby synagogue. His name is Avromi. The minute he met Saul, I knew that we had found our teacher. He was a natural, had a wonderful voice, a warm and engaging personality, and, most importantly, he was motivated to make it happen!

Tip

Saul's film can be viewed on our website, where you can also read about other inclusive b'nei mitzvot – you can show this film to young people preparing for their Bar/Bat Mitzvah or other groups in your community. None of us knew what the Bar Mitzvah would be. We took it a step at a time, working it out as we went along. Avromi worked with Saul on his articulation, and breathing; starting with basic sounds such as 'Baaaaah' 'Maaaaah', moving onto more complex Hebrew sounds such as 'CH'. I made cards with single phonetic words in very large font which Saul could read. I put pictures on them, to help Saul to read the sounds and to attempt to understand the abstract concepts in the prayers. We laminated them with non-reflective plastic and used coloured backing to help Saul differentiate each word on each page, starting with one word at a time. Every little detail about how it was presented made a difference to Saul.

Slowly, and with much perseverance, Saul learnt the 2 prayers for being called up. And with his newly developing voice and skills, Saul went on to learn the Torah reading for Rosh Chodesh, the New Month, too! We picked a Sunday Rosh Chodesh, to enable us to drive and use a microphone to amplify Saul's very slight voice.

Despite being very ill, Saul sang his portion beautifully. It was an amazing triumph, the culmination of all of our hard work to celebrate the life of our special son. We marked his 'coming of age', just like other children of his age, but in a unique way that worked for him.

After the Bar Mitzvah, Saul continued to have his weekly lessons. Our Shul now has a new Rabbi. He has made it a priority to get to know us, be inclusive of Saul and to find an opportunity for Saul to have a celebration to honour him in our own synagogue. He was very honest, admitting that he had not worked with people with special needs before but wanted to learn and make it work.

When Saul was called up to the Torah on the bimah of our synagogue on his 18th birthday, many tears were shed. It was marvellous to hear Saul singing with improved accuracy and he clearly enjoyed being called to the Torah. We also planned a party on Sunday afternoon, with the theme 'Chai', Life, which has a numerical value of 18.

Since then, Saul has been given the honour to sing Avinu Malkeinu as a solo on Rosh Hashanah and to join the synagogue choir. He has joined the shul Klezmer band as a drummer and they have performed at Saul's birthday party, as well as at two synagogue fund raising events. Saul loves it all, finding it fun and enjoying being fully included.

A Bar Mitzvah is a special day for any Jewish young person, and their family. But it is also part of a journey to being a Jewish adult, taking on responsibilities and becoming part of a community. If Saul had not had his Bar Mitzvah he would be a very different person today; having a Bar Mitzvah enriched his life immeasurably.

Being denied a Bar Mitzvah would also have left Saul's sisters, as well as my husband and I, feeling distanced from the Jewish community.

Exclusion affects the whole family. Inclusion benefits the individual, the family and the whole community; Saul's musical contribution and his vibrant personality enrich services and community events. In sum, Saul has come such a long way, but he still has lots to learn - as we all do!"

### **Working with Carers**

Many people with learning disabilities or mental ill-health may be supported by carers, or support workers, who are not Jewish.

Read some statements from carers about supporting people to go to synagogue and Jewish community events.

Think about what helps carers to feel able to support someone to go to synagogue:

> I didn't know what I should do at the synagogue, where to go or where to sit. I felt totally unable to support the person I was with

We weren't sure if we could drive there, or park in the car park, on a Saturday

Limmud L'Am (inclusion day at Limmud conference) was amazing – everyone was so friendly and helpful and there was so much going on

> I wasn't sure what to wear – I normally come to work in jeans and a t-shirt

Tip

Carers can get more information about the Jewish community on The Judith Trust website, under 'Information for support workers and care staff'. The person I support loves going to synagogue and always looks forward to the weekend

Someone told me about the luncheon club and now the person I support enjoys going every week

> Having someone to sit with, and ask questions, made us both feel more comfortable

We have a volunteer who comes to the house regularly. When someone wants to go to synagogue, we call him a few days before and he will meet us at the door, or ask someone else to do so if he is not around

> The Rabbi always comes to say hello to us and it makes me feel it's good to be there

> > Remember to add to your Action Plan

### **Supported Volunteering**

The Jewish community runs on a huge base of fantastic volunteers – from those stuffing envelopes, handing out flyers or collecting donations in charity boxes, to Trustees and synagogue Chairs, the community could not function without them. And, as the Chief Rabbi, Rabbi Jonathan Sacks said "The paradox of volunteering is that the more we give, the more we are given" (The Times, June 2005).

People volunteer for many reasons – wanting to help others, wanting to give to a cause which is close to their heart, to gain work experience, to use their skills, to fill their time...the list goes on. By volunteering, people make friends, grow in confidence, gain self-esteem and become part of a community or organisation. Volunteering is a great opportunity for everyone, including people with learning disabilities/mental health problems.

# When supporting people with learning disabilities or mental health problems to volunteer, there are factors to consider throughout the process:

#### Recruitment

- From the start, think about diverse needs
- How will people find out about the opportunities?
- What information will you give them?
- How do they apply?
- Make sure you match the person to the role carefully
- Be open and talk about support needs from the start

#### **Getting started**

- Have support in place from the start
- Make a plan for withdrawing the support if appropriate
- Make a careful induction plan which considers the individual's needs
- Offer training as appropriate, but make sure it is accessible and inclusive
- Ensure the team the person will be working in is friendly, welcoming and supportive

#### **Ongoing support**

- Ongoing support should come from within the organisation from peers and mentors
- The person should receive supervision, training opportunities and progression opportunities
- Does your existing support structure need to change to accommodate individual needs?
- Do you know where to go and get the information and support you need?

# Examples of reasonable adjustments and support strategies



# Jon has autism and needed help remembering what to do when in his cleaning role

A picture sequence of what to do ensured he remembered what to do when, and labels on the outside of the cupboard helped him find things easily. Jon is now working independently.

# Rachel works in a shop but found it difficult to handle cash correctly

Rachel is going to a local college to do a free course on money management. In the meantime, she is doing other tasks in the shop, and has learnt to use the credit card machine.

# Josh sorts the post in an office but found it hard to remember everyone's names, and where they sit

Everyone has put a photo of themselves, and their name, on their desk. Other people have also said they find this very helpful!

#### Susan worked in a community centre café washing up. She wanted to help prepare food but needed a food hygiene certificate

Susan's mentor helped her to understand the food hygiene regulations by working on a small area every day, for just 5 - 10 minutes. She also showed her what the rules meant in practice in her kitchen, which helped her to understand them better. Susan passed her test!

#### Chloe wanted to volunteer in her shul but didn't really know what she wanted to do

Her mentor worked with the shul office to find a few different jobs for Chloe to try – filing, answering the phone, preparing the kiddish and tidying the nursery toys. The mentor then helped Chloe to think about each job and what she liked or did not like about it, so she could make a choice about what to do.

\*Above photograph: Langdon Brady Club members prepare Mishloah Manot (Purim gift bags) for Jewish Women's Aid, as part of their Yoni Jesner Volunteering Award

Tip

The Judith Trust and The Jewish Volunteering Network (JVN) aim to offer mentors to people with additional needs who want to volunteer – just get in touch!

# **Action Plan**

Complete the table to consider how you can achieve the ideas you have read about, as well as adding your own ideas at the end of the table.

How										
Action	Copy the 'getting started' quiz (p4) and use it in a meeting about inclusion.	Ask the Rabbi to give a sermon about inclusion.	Ask people with learning disabilities and/or mental health problems to be involved in the project.	Recruit and train buddies for adults and children.	Make a statement about inclusion on your website.	Do a tour of the building for people interested in getting involved; explain what happens here.	Share our guide to 'Accessible information' with people producing written information for your organisation.	Send flyers to local care providers.	Look at the 'Recources for Communities' on the Judith Trust website.	Have a Jewish Individual Education Plan for your cheder - train your staff how to use this.

<ul> <li>Watch Saul's Bar Mitzvah film individually, or as a group.</li> <li>Jaentify a quiet space where people can go if needed.</li> <li>Check your organisation's Safeguarding procedure and develop it as needed.</li> <li>Get to know the carers of the people getting involved.</li> <li>Tell carers there is information about going to shul on the Judith Trust website.</li> <li>Get involved with the Judith Trust and JVN supported volunteering project.</li> </ul>	

### **Glossary of Jewish words:**

Ark – the cupboard where the Torah (scrolls with the Old Testament on) are stored
Bar / Bat Mitzvah – a coming of age ceremony. Girls have a bat mitzvah at the age of 12 or 13; boys have a bar mitzvah at the age of 13.
Bimah – the platform from which the service is led in the synagogue
Cheder – religious education classes for children
Kiddush – wine and refreshments served at the end of a synagogue service, with a blessing
Kippah – a Jewish skull cap
Rabbi – the religious leader of a Jewish community
Shabbat – the Jewish Sabbath, day of rest, from sunset on Friday to sunset on Saturday.
Shul / Synagogue – the Jewish house of prayer
Torah – the scrolls with the Old Testament on, which are read in the synagogue on Monday, Thursday and Saturday

Yom Tov – a Jewish festival, when the same rules apply as for Shabbat (Sabbath)

### **Glossary of Social Care Terms:**

Please visit these pages to understand more about these terms

Challenging Behaviour – p22 Learning Disability – p6 Makaton – p17 Mental health / Mental illness – p7 The Social Model of Disability – p13 Special Needs – p26

# **Useful Organisations and Websites**



www.jamiuk.org 020 8458 2223



www.langdon.info 0845 600 6562



www.met.police.uk 999 (emergency) or 101 (non-emergency)



www.nhsdirect.nhs.uk 111



www.jewishcare.org 020 8922 2000



www.norwood.org.uk 020 8809 8809



www.kisharon.org.uk 020 8457 2525



www.jweb.org.uk



www.childline.org.uk 0800 1111 The Judith Trust Inclusion Campaign works to ensure that people with learning disabilities and/or mental health problems are able to be involved in the Jewish community in whatever way they choose.

This book will help communities and organisations understand more about inclusion and how to make this happen:

- A basic understanding of learning disabilities and mental ill-health
- Discover how being part of the Jewish community can promote mental well-being
- Be aware of the barriers to inclusion
- Recognise how to overcome these barriers to promote inclusion
- Formulate an action plan for promoting inclusion within your synagogue or organisation



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To find out more about our work, to get involved or to make a donation please contact us





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