Parents as ALLIES

Toolkit

Contents

Background

Some parents of Disabled children have struggled to achieve the rights of their Disabled child particularly when it comes to inclusive education.

It is important that parents of Disabled children / children labelled with Special Educational Needs and Disability (SEND) (the term used by families and parents for the purposes of this toolkit) participate in advancing the right of their children to be included in mainstream education. Parents have a big influence over their children and therefore should be encouraged to seek inclusive education in mainstream educational settings as a valuable tool in helping children realise their aspirations to be included in society when they become adults.

This training toolkit is designed to enable Disabled people's organisations (DPOs) to engage with parents. The toolkit will also help DPOs train parents, enabling them to understand the principles of inclusive education, the Social Model of Disability and other important values that are empowering for parents, their children and for young people.

Partnership work with parents will help to pass on this experience to DPOs. This toolkit will achieve that by connecting DPOs with parents and forming close relationships that will enhance supporting the inclusive education rights of children and young people. We believe DPOs should become hubs of campaigning, innovation and action for Disabled children/young people with parents acting as allies to their children and young people. This also helps to ensure the legacy of the work of DPOs through the involvement of Disabled young people.

How to use this toolkit

We know DPOs are leading the way in fighting for Disability equality and empowering Disabled people. We hope that this toolkit will help DPOs to enable the parents of Disabled children and young people to start campaigning and advocating for the rights of their children in mainstream education using the principle of inclusive education.

The toolkit is also designed to enhance better cooperation and partnership between DPOs and to enable parents to become better allies to their children and young people and to help raise aspirations for their children and young people.

This toolkit has been co-produced by ALLFIE and two parents of Disabled young people. The design and layout is similar to our Knowledge is Power toolkit which was co-developed by young people.

We advise initial delivery of this toolkit should be with an experienced Disabled person and a parent or family member who understands the Social Model of Disability and Independent Living. We would also advise that some activities and sessions will work really well if Disabled young people, a DPO staff member and parents are involved (see session 3).

The activities have been developed so you can deliver them flexibly, but ideally in order. For example, you may wish to cover all of the sessions in one full day session or in 2-3 shorter sessions. You can use one or all activities in a session, depending on the time available. You may wish to spend longer on each session to ensure it is accessible to everyone.

The Alliance for Inclusive Education (ALLFIE) is an organisation of Disabled people and allies which campaigns for the right of all Disabled pupils and students to mainstream education as part of the building of a more inclusive society. Disabled and non-Disabled learners learning together creates a more inclusive society. www.allfie.org.uk

Session 1

Understanding Disability: Who is my child? Who am I?

Overview

Despite advances in Disability equality, many Disabled children and young people are still growing up without a positive identity as a Disabled person. This is particularly evident for children with intersectional identities. What this means is there is an overlap of a person's various identities for example race, gender, sexuality, and class which contributes to specific types of oppression and discrimination. Many parents of Disabled children and young people and their children do not have any Disabled role models, have little or no understanding of the history of Disability and have had little contact with the Disability community or their local Disabled People's Organisation (DPO).

The aim of this session is to support the parents of Disabled young people and children to explore their identity as parents and their child's identity as a Disabled person, and to understand the Social Model of Disability.

Does the group know each other? If not, you may wish to use one of the icebreakers in the appendices.

Key topic	Aims	Activities
1.1 Who am I? Who is my child? What does Disability mean to you?	• To explore parents of Disabled young people's understanding of Disability, of their child's identity as a Disabled person and their own identity	• Who is my child? Person outline • What Disabled people were in your life growing up? • Listening exercise
1.2 Who are we? Understanding the oppression – parents' perspective	• To develop parents' understanding of Disability history and the Disability rights movement. • To enable parents to see themselves as part of a community. • To enable parents of Disabled children and young people to understand oppression.	• Timeline: What is Disabled people's history? • Presentation on parents' perspective and discussion
1.3 Disabled People's rights and experience: The Social Model of Disability	• To develop parents of Disabled young people's understanding of the Social Model and what this means in terms of identity and support. • To enable parents of Disabled young people to understand the barriers Disabled people face and how this affects their self-identity, confidence and involvement in decisions about their lives. • To explore how the Social Model actively supports involvement in decision-making.	• What disables us? The Medical Model and Social Model of Disability. • Understanding the Social Model: The Line of Truth

Key Messages

(to be repeated at every session)

- Disabled people have experienced discrimination and exclusion.
- Parents of Disabled children and young people experience oppression (see Activity 1.2).
- The Disabled people's movement has fought for rights for Disabled people.
- Disabled people are a community that continues to campaign for equality.
- Disability is a positive identity to be reclaimed/embraced (Cultural Model of Disability).
- Disabled people are Disabled by attitudes, inaccessible environments and a lack of equality, not by their impairments. This means that the world needs to change and become more inclusive of Disabled people.
- Disabled people have the same rights as non-disabled people, including to be involved in decisions about their lives.

1.1 Who is my child? Who am I? What does Disability mean to you?

Aim

- To explore and understand Disabled children and young people's understanding of their own identity as a Disabled person and your identity as a parent.
- There are two options for the activity for this section - you can choose from either **Activity 1** or **Activity 2**

1.1 Activity 1: Who is my child? Person outline

Requirements:

- Large sheet of paper
- Coloured pens
- Tape or Blue Tac

The Activity

1. Draw an outline of a person on a large sheet of paper.
2. Stick the sheet of paper to a wall, tape it to a large table or lay it on the floor – whatever makes it easier for everyone to see it and add to it.
3. Starting off on the inside of the person, ask the parents to write or draw what Disability means to them as an individual and how they see their Disabled child.
4. Ask the parents to write around the outside of the person what they think other people think about their child.
5. Feedback: Depending on the group you can:
   - discuss what parents are writing as they go along or wait until the end of the activity and then ask parents to describe what they've drawn or written.
   - extend the discussion by exploring why people think these ways about disability. What impact does this have on Disabled people? What impact does this have on parents?
6. Summarise by explaining that these sessions are about exploring and understanding more about Disability and developing a positive identity of Disabled people and of yourselves.

1.1 Activity 2: What Disabled people were in your life growing up? Listening exercise

Requirements:

Space in the room for
parents to listen in pairs.

The Activity

1. Get parents into pairs.
2. Ask each pair to think of the Disabled people who were in their lives growing up and the impact they had.
3. Ask each parent to spend a timed 5 minutes sharing this and then swap over – this is a listening exercise.
4. Then ask each pair to think about and share the impact upon them of their growing up experience and the reality today – again 5 minutes each listening.
5. Ask for any parents willing to share their perspective.

1.2 Who are we – understanding Disability history and oppression

Aim

- To develop parents of Disabled children and young people's understanding of Disability history and the Disability rights movement.
- To enable parents of Disabled young people to see themselves as part of a community and to understand oppression/parents' perspective.

1.2 Activity 3: Timeline: What is our history?

Requirements:

- Prepared images of key events from disability history – positive and negative (quantity can be adapted depending on the access requirements of the group) e.g. 12 Pillars of Independent Living, UNCRPD, Disability Discrimination Act, the right to mainstream education, the Social Model, the Equality Act, Direct Payments, Personal Budgets.
- Dates for each of the events on a timeline (see suggestions in appendix, p56).

Tip:

To personalise the activity you could add in important dates for the DPO or the community/locality

The Activity

1. Lay out the images on a table.
2. Ask the parents to put them in order of oldest to most recent and match them with the date cards on the timeline.
3. They can do this as a whole group or in smaller groups with a set of event cards and date cards for each group.
4. Ask the group (or each group in turn) to say in which order they think the events happened.
5. Move the events around to put them in the right order.
6. Give a brief explanation of each of the events, the challenges Disabled people faced and the impact each has had on Disabled people's lives, independence, choice and control.

1.2 Activity 4:
The oppression – parents' perspective

Requirements:

- Crippen postcards
- Micheline's images
- Statements about parents (Sheet 1 and 2)

The Activity

1. Lay out images drawn by Micheline and statements to do with parenting on Sheet 1 and 2 below, Crippen postcards etc.
2. Invite comments.
3. Discuss as a group the impact of the oppression on our relationship with our children.

Parent – What **should** this mean?

- A parent can be described as a person that cares for and protects you. A person that gives you the tools to enable you to lead the most fulfilling life possible. Someone that teaches you to love to learn, and love to give/take and co-live with others.
- A person who loves you unconditionally, and backs you no matter what, because they trust you completely.
- A person who teaches you right from wrong, but respects your judgement when it is given.
- A person that accepts you for what you grow into, and believes (ALWAYS) that you are doing the best you possibly can.
- (Someone that does not impose their views as final, and nag you to become what they want, rather than what you are).
- A person who in turn receives honour, trust and love without question and in complete trust.

Parents' Oppression

What are the demands that society makes on parents?

- To be perfect, rather than the best they can be
- To be criticised, rather than understood, helped and supported
- To be solely responsible for the young person their baby becomes
- To be made to feel guilty for every shortcoming of that young person
- To produce a PERFECT young person in every way!
- In short to produce the impossible – rather than the achievable
- Parents of Disabled children spend their life justifying what they/their offspring can and can't do. Why? Society always had a better idea and is always ready to impose a value judgement.

1.3 Disability – whose problem is it?

Aim

- To develop parents of Disabled children and young people's understanding of the Social Model and what this means in terms of Disabled people's identity.
- To enable parents of Disabled children and young people to understand the barriers Disabled people face and how this affects their self-identity, confidence and involvement in decisions about their lives.
- To explore how the Social Model actively supports involvement in decision-making.

1.3 Activity 5: What disables us? The Medical Model and the Social Model

The Activity

1. Brief introduction to explain that Disabled people are disabled by attitudes, inaccessible environments and a lack of equality, not by their impairments. This means that the world needs to change and become more inclusive of Disabled people.
2. In small or whole group, ask the parents to think of some examples of different types of impairments. Write these on flipchart paper. Summarise:
   - Disabled people have many different types of impairments. These are just part of who we are.
   - Our impairments may cause us some difficulties but they do not disable us.
3. Explain that people are disabled by barriers in the world around them. Stick up the three headings on the wall: negative attitudes, inaccessible environments, lack of equality and rights. In small groups or as one large group, ask parents to think of examples of barriers that Disabled people face.
4. Show a short video of the Social Model: www.youtube.com/watch?v=23oBOjQAYe8 or www.youtube.com/watch?v=ObMG6-3QXws
5. Summary: Show slides or a handout to summarise the difference between the Medical and Social Models.
   - Disabled people have many different types of impairments. These are just part of who Disabled people are.
   - Disabled people's impairments may cause them some difficulties but they do not disable them. They are disabled by the world around them.

(cont.) 1.3 Activity 5: What disables us? The Medical Model and the Social Model

Requirements:

Social & Medical Model slides
(see following pages)

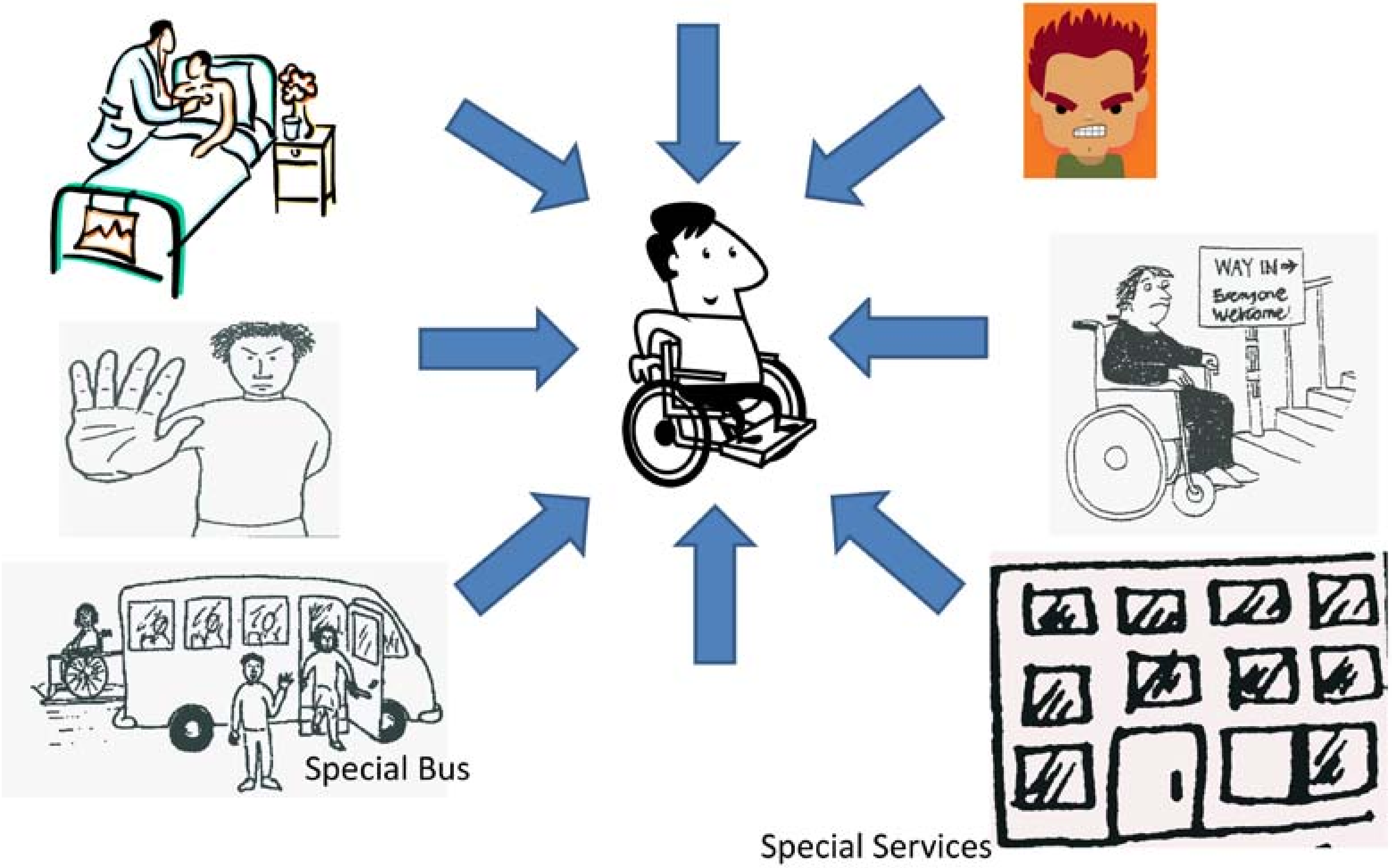
Key messages

- Disabled people are not disabled by their impairments.
- Disabled people are disabled by barriers in the world around them.
- The Social Model is important because it gives power back to Disabled people. It enables them to identify and challenge barriers in their lives that disable them.

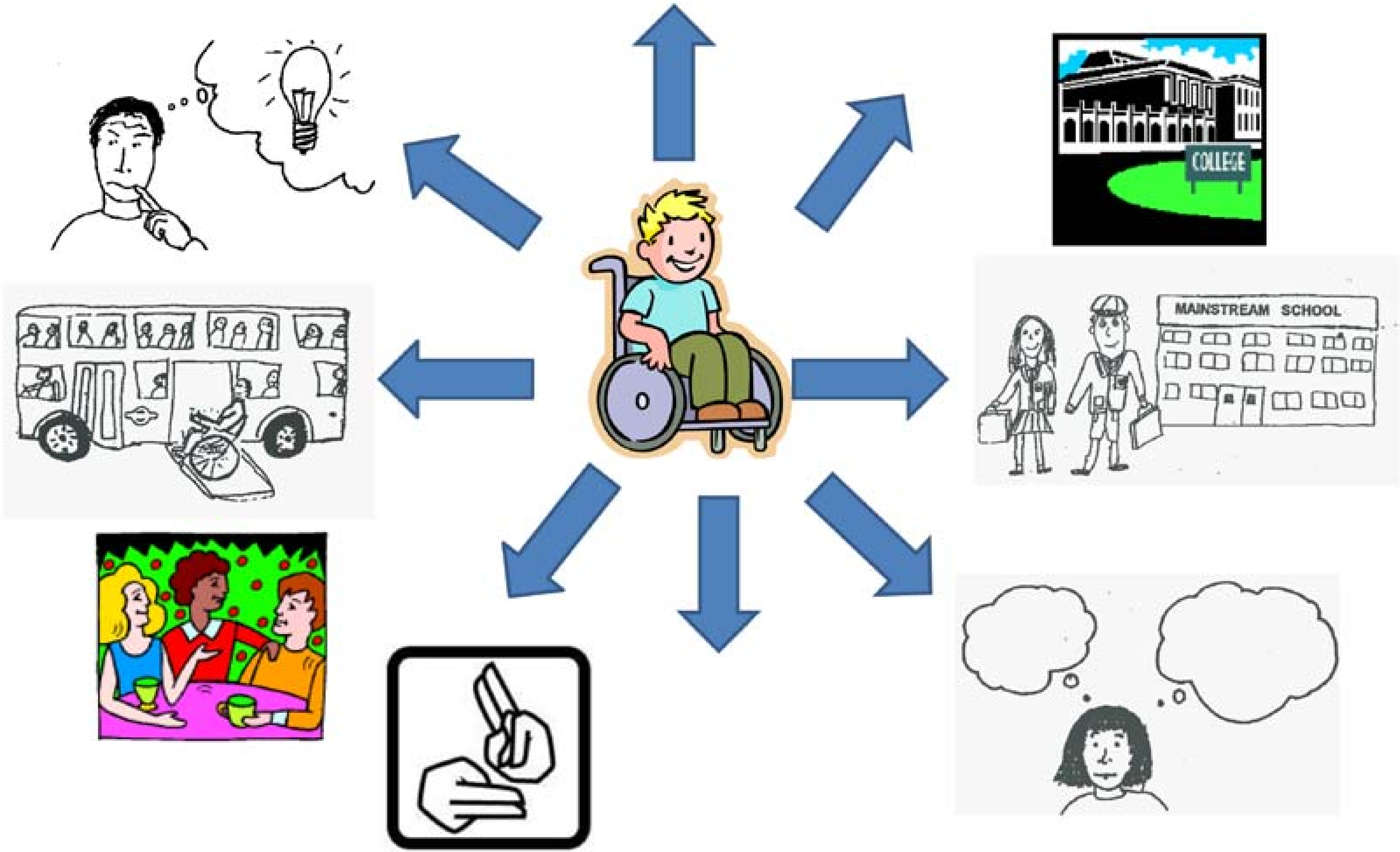
Tips

1. To help the discussion you could:
   - prepare examples of different types of barriers
   - prepare some short examples of a Disabled young person's experiences. Read this out and then ask parents to think about what the barriers are.
   - If there are good dynamics and the group are supportive of each other, you could ask parents to think about and share examples of times their children and young people have not been able to do something – then discuss what the barriers were. Support them to think about the barriers in society.
2. Bear in mind that people accessing the training may have a lack of empowerment and be very used to the Medical Model. It's important to allow them to explore this different way of seeing disability; adapt the activity to make it relevant for the group you are working with.

The medical model of disability



The social model of Disability



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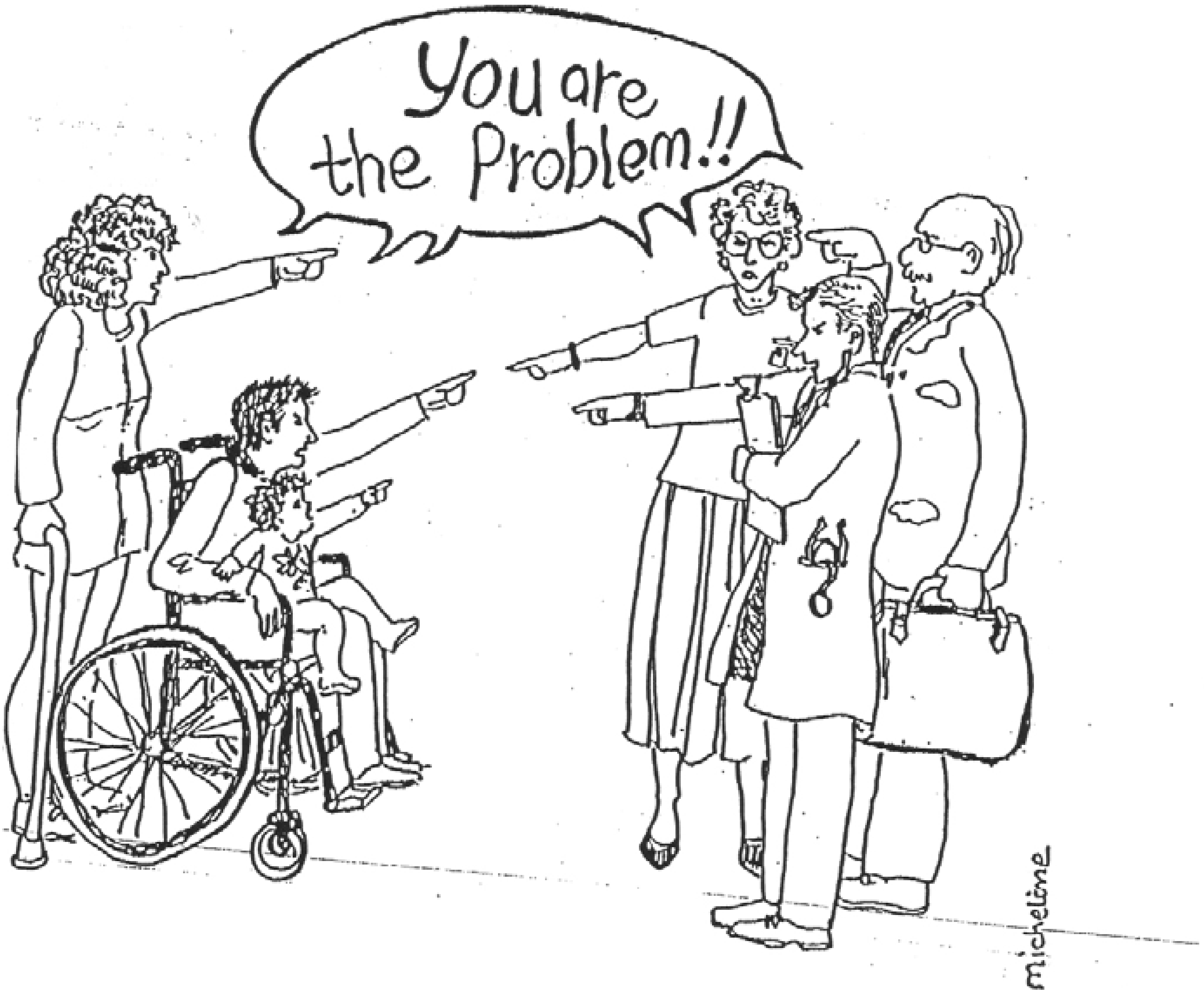


The Medical Model

Child is faulty

↓

diagnosis

↓

labelling

↓

impairment becomes focus of attention

↓

assessment, monitoring, programmes of therapy imposed

↓

segregation and alternative services

↓

'ordinary' needs put on hold

↙ ↘

re-entry if 'normal' enough

permanent exclusion

The Social Model

Child is valued

↓

strengths and needs defined by self and others

↓

OUTCOME based programme designed

↓

resources made available to 'ordinary services'

↓

training for parents and professionals

↓

relationships nurtured

↓

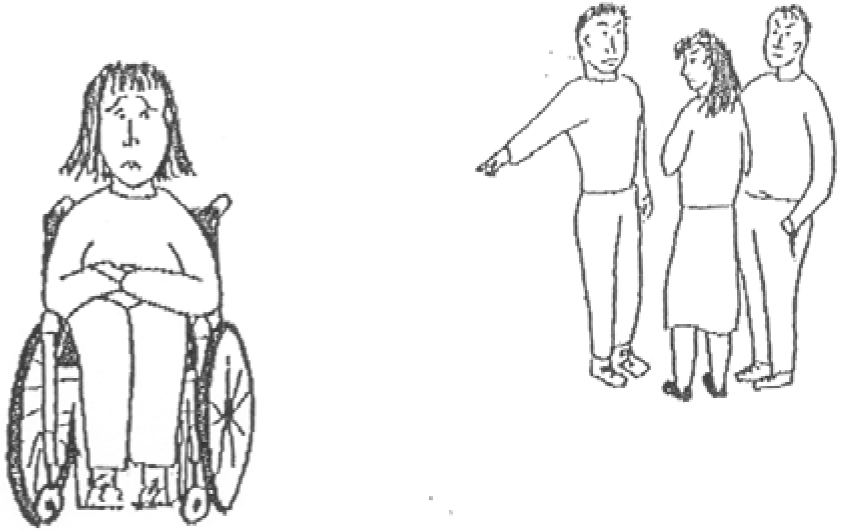
DIVERSITY WELCOMED

↓

Society evolves

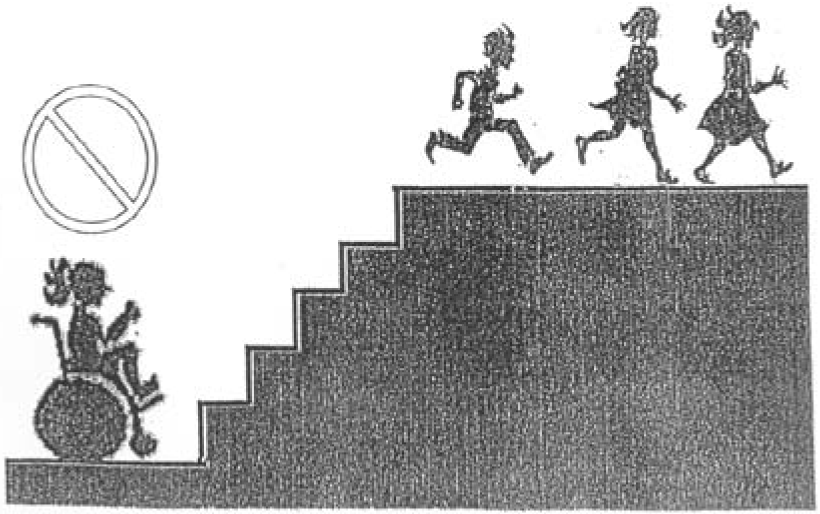
(7/7)

The Medical Model



Social providers say:
“You are the problem”

The Social Model



Disabled people say:
“Barriers are the problem”

(1/2)

1.3 Activity 6: Understanding the Social Model: the line of truth

Requirements:

1. Print out two signs that can be pinned to the wall in large font – one reading 'Social Model' and the other 'Medical Model'
2. A list of statements or situations written from a Social Model or Medical Model perspective. These could include:
   - Disabled people /people with disabilities
   - Disabled toilet / accessible toilet
   - Special needs transport / accessible transport
   - Disabled people are the problem / people's attitudes are the problem
   - It's my fault I can't get into that building because I am in a wheelchair / the building needs to be wheelchair accessible
   - This model was created by medics/this model was created by Disabled people

Tips:

- If you have less space, you can hold up red and green cards to show whether they think the statement is true or false
- If the group are shy, you could do this activity in teams to stop people feeling singled out.

(cont.) 1.3 Activity 6:
Understanding the Social Model: the line of truth

The Activity

Note: you do not have to use all of the example statements given.

1. Use the illustrations as discussion tools.
2. Use a test statement to model how the activity works eg "This model was designed by medics".
3. Everyone to gather in the centre of the room.
4. Stick the Social Model of Disability and Medical Model of Disability signs at opposite ends of the room.
5. Read each statement to the group, giving them time to decide.
6. Parents to move to the corresponding end of the room (or some way along the line if they're not sure).
7. Do not tell them if they've chosen correctly.
8. You can repeat this exercise at the end of the day to evaluate parents' learning, telling them the answers at the end.
9. If you're not going to repeat the activity, give the parents the answers as you go.
10. If the group are working well together take the opportunity to ask individuals why/how they made their decisions.

Session 2

My child's rights and choices: Making decisions about my child's life

Overview

This section aims to support parents of Disabled children and young people to be able to support their children, and also to develop their children's skills and confidence to be involved in decisions in their lives. Many have little or no experience of being involved in decisions, and experience decisions being made about them. Many also have limited or no knowledge of their right to be involved in decisions and therefore often feel like any involvement is positive.

It is hoped that this section will enable parents to know that their children have rights to be involved in decisions in their lives; to support them to explore how to make choices and decisions; and to explore and identify who can support them to make choices and decisions. It also introduces relevant legislation.

Key topic	Aims	Activities
2.1 What are your child's rights?	• To enable parents of Disabled children and young people to understand the law and that it is their child's right to be involved in all decisions that affect them	• **Activity 7:** Brief presentation on rights and decision-making e.g. UNCRC, UNCRPD • Specifics re: age, involvement – eg when you can make your own decisions, when others make decisions, how you should be involved etc. • See also Useful Resources page in the Appendices (p65) • Relevant legislation
2.2 Supporting your child's choices and decisions	• To enable parents to be an ally to their child to help them learn how to make choices and decisions	• **Activity 8:** role of allies • Micheline Mason's statement • What you love about your child – listening exercise • Discussion
2.3 Who can support you and your child to make choices or decisions?	• To support parents to think about who can support them and their child to make choices and decisions	• **Activity 9:** Circle of support • Participants fill their own in

2.1 What are your child’s rights?

Aim

- To enable parents of Disabled young people to understand that it is their child’s right to be involved in all decisions that affect them.
- Key legislation listed
- The key clauses:
    - ‘Nothing about us without us’ legislation
    - ‘Reasonable adjustments’
    - Equality Act 2010 - clauses
    - Education Act
    - Children’s Act
    - Children and Families Act 2014
    - UN Conventions

2.1 Activity 7: My choice, my rights

Requirements:

- Brief presentation on rights (refer to timeline)
- Legislation

The Activity

- Brief presentation

Key messages

1. Disabled young people have the right to be involved in all decisions that affect their lives.
2. All Disabled children and young people have the right to be involved in decisions that affect them.
3. Not being involved in choices and decisions can make Disabled people feel less confident and affect their self-esteem. This can make some Disabled people think they cannot make choices for themselves.
4. It is important that Disabled children and young people are supported to learn how to make choices and decisions.
5. Parents can be allies to their children.
6. Parents and children need allies too – to help make good choices and decisions and good outcomes.
7. This helps Disabled people to become independent.
8. Relevant legislation.

(cont.) 2.1 Activity 7:
My choice, my rights

How can I be an ally to my child while they are in education?

The following case study highlights that while positive parental involvement with their child's school is a key ingredient to helpjng ensure their child experiences better educational outcomes, one of the most important ways a parent can support their disabled child's rights within education is to know the law that protects those rights and how to apply it:

Did you know that the UN Convention on the Rights of Persons with Disabilities (UNCRPD), Article 24 states: "States Parties recognise the right of persons with disabilities to education. With a view to realising this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive, education system at all levels, and life-long learning."

The Children and Families Act 2014 within its code of practise section 66 expects that any school or educational institution use its best endeavours to secure that the special educational provision called for by the pupil's or student's special educational needs is met. This would include requesting a statutory assessment which could lead to an EHCP (Education, Health and Care plan).

The Equality Act 2010 section 20 states that schools and institutions have a duty to make reasonable adjustments to include a disabled student.

The Equality Act also protects against disability discrimination - when someone is treated less well or put at a disadvantage for a reason that relates to their disability.

How can I be an ally to my child while they are in education?

Case study

K is a 14 yr old mixed heritage boy, living with his mother and at risk of being permanently excluded from his school. His mother was supported by an education advocate to meet with the head teacher and the SENCO of the school to explore alternatives to exclusion and to look at what other support and approaches could be used to include K.

The school maintained that K's behaviour was such that it warranted permanent exclusion and they also maintained that they could not meet his needs. K has an EHCP.

K's mother with advocacy input was able to remind the school that K is disabled and so excluding him would be discriminatory. She also reminded the school of their other statutory duties under the law, to make reasonable adjustments and use their best endeavours to ensure K received the support he is entitled to.

Despite this the school still maintained that they could not meet K's needs and that he would be better off at a special school. K did not want go to the special school and wanted to stay at his current school with his friends.

K's mother, as his ally, made sure that K's views and wishes were heard and again reminded the school that they could not exclude K on the basis that they could not meet his needs (Government Exclusion Guidance section 13).

Once the school realised that they could not simply get rid of K and that they had a responsibility to do all they could to ensure his needs were met, they agreed to an annual review to look at his EHCP and see what other provision and resources might be required to support his inclusion.

In K's case it was particularly important for his mother to be able to work in partnership with the school to keep him meaningfully included and educated. His older brother had been excluded from school and was now in prison, and whilst K had been temporarily excluded from school he too had got involved in criminal activity associated with a local gang and was known to the police.

His mother will continue to support K as his ally to enable his successful educational outcomes.

2.2 Making choices and decisions

Aim

- For parents to think about how to enable Disabled young people to learn how to make choices and decisions.
- To understand the importance of allies and listening.

(1/3)

2.2 Activity 8: Role of Allies

Aim

To think through what it is to be an ally to a Disabled person.

Requirements:

- Micheline’s statement (next page)

Aim

- The aim of this activity is to think through what it is to be an ally to a Disabled person. Share Micheline’s statement (on the next page).
- Invite discussion.
- Ask parents what they love about their child – share with their partner (listening exercise: 3 minutes each way plus feedback).
- Discuss how parents can be meaningful allies to their children/young people using this approach.
- Share listening resource.

How to be an ally: the role of non-disabled people

The truth is this:

We do need you, not to be "experts" or managers of our lives, but to be friends, enablers and receivers of our "gifts" to you. We need you to admit cheerfully what you don't know, without shame; to ask us what we need before providing it, to lend us your physical strength when appropriate, to allow us to teach you necessary skills; to champion our rights, to remove barriers previously set in place, to return to us any power you may have over our lives. We may also need you to remind us of our importance to the world to each other, at times of tiredness and discouragement. We can live without patronage, pity and sentimentality, but we cannot live without closeness, respect and cooperation from other people. Above all we need you to refuse to accept any "segregation" of one group of humans from another as anything else but an unacceptable loss for all concerned.

Micheline Mason, from *Disability Equality in the Classroom: A Human Rights Issue*
Richard Reiser/Micheline Mason

(3/3)

Listening – what is that?

- Attending to everything the other is saying and expressing, with respect and no judgement.
- Helping the speaker to think more deeply by being encouraging.
- Being open and receptive. That allows the speaker to remain alert and focussed.
- There is never any need to attribute blame.
- Acknowledging mistakes for what they are: learning opportunities.
- Acknowledging each and every achievement.
- Because listening can bring up feelings in the listener, s/he must make time and space to explore and express these in a supervision, debriefing or organised listening/talking time with a friend. The feelings in the listener do not need to interfere with the speaker's listening time.

2.3 Who can support you to make choices or decisions

Aim

- To support parents of Disabled young people to think about who can support them and their child to make choices and decisions.

2.3 Activity 9: Circle of Support: person-centred planning

Aim

To explore who Disabled young people and parents can get support from to make choices and decisions

Requirements:

- Circle of support template.
- Circles of support on A4 paper (see following pages).

The Activity

1. Ask the parents to sit or stand in a large circle.
2. Explain that we are going to think about who can help us and our children to make choices and decisions.
3. Ask one person to volunteer to stand in the middle of the group. Ask them to think of a different persona to be eg Jenny is a 17 year old young woman who lives at home with her parents.
4. Explain we are going to think about all the different people who could help the young person in the middle to make choices and decisions eg mum, sister, teacher, friend etc.
5. When a parent from the group makes a suggestion, tell them they now have to pretend they are the person they have suggested eg a friend. Ask them to stand close or far away to show how much they think the parent would trust this person to help them make a choice or decision.
6. Keep repeating until all the parents have a role.

(cont.)

(cont.) 2.3 Activity 9: Circle of Support

The activity (cont)

7. Now think of a decision the person in the middle needs to make eg shall I go to the party tonight? Discuss how the amount of help each person in the circle can give changes for this decision. What if the decision was about what school/college/ university to go to?
8. Once the discussion has finished, parents can make their own circle of support – one for their child, one for them -then write their child's name and their name in the middle circle. Ask them to draw or write the different people in their lives that could help them to make choices and decisions.

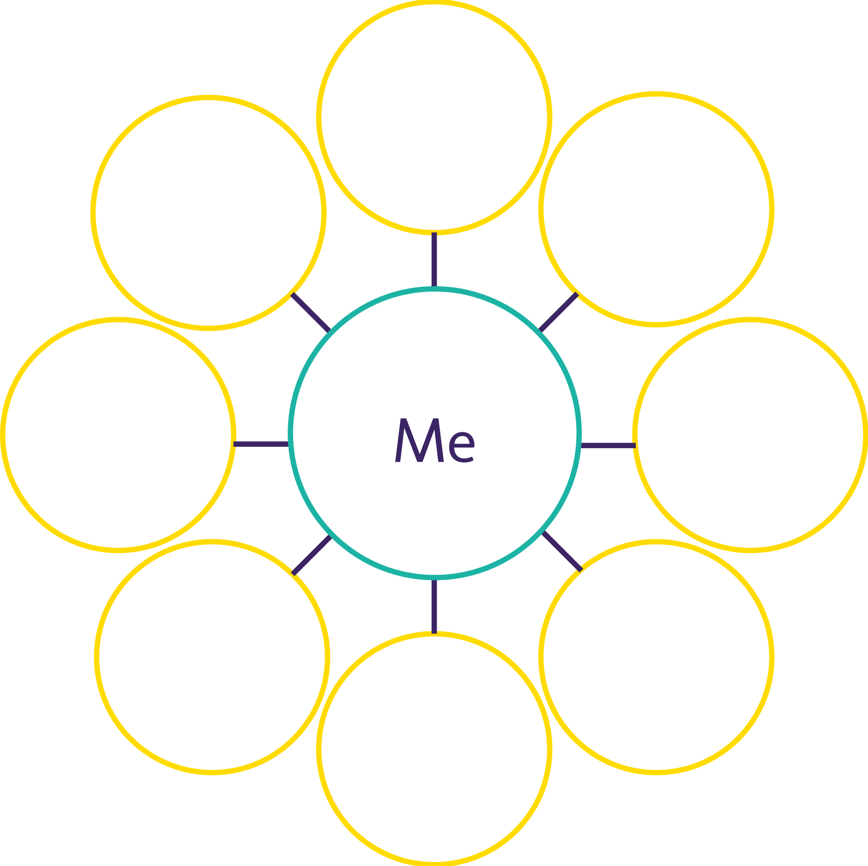
(NB: Throughout the exercise make sure parents are putting their child's needs and wishes at the centre)

Tip:

If you don't have enough space to stand in a circle, you can draw the circles on flipchart paper and add dots to show where various people are.

(3/3)

Activity 9: Circle of support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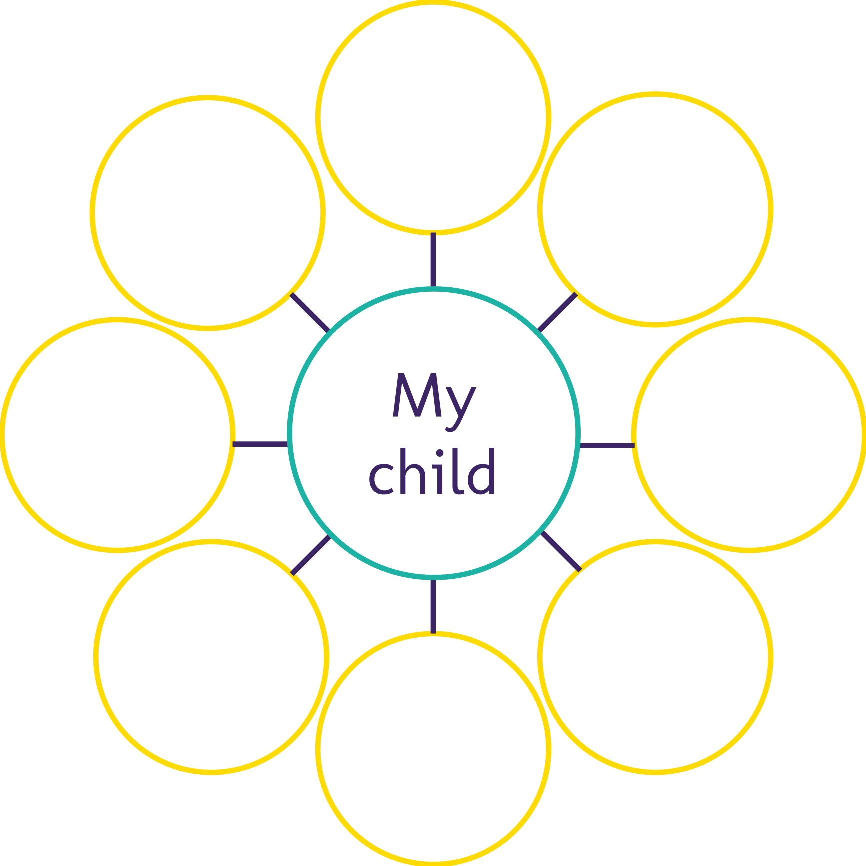

My child

Session 3

Disabled young people, Disabled adults: the big issues

Overview

The aim of this section is to enable parents of Disabled children and young people to explore why it is important to work together with each other and DPOs to harness the experience and expertise they both bring and share, and to think about some of the big issues together.

Key topic	Aims	Activities
3.1 Parents, Disabled young people and DPOs planning positive futures	• To explore why is it important for parents of Disabled children and young people to get involved with DPOs to support inclusion, aspiration and independence	• Activity 10: The big issues • Activity 11: What is a good life – Draw up timeline for PPF for your child • Activity 12: I can, You can, We can!
3.2 What do we need?	• To support DPOs and parents to support and enable a good life for their children.	• Activity 13: Who and what can help? • Listening exercise • What is available?

3.1 Activity 10: The Big Issues

The Activity

- Brainstorm and debate the big issues – inclusion, aspiration, etc.
- Use the Inclusive Education statement (page 43) as a starting point for debate
- Use Appendix: What Disabled People Want (page 60) to stimulate discussion on independence v interdependence and aspiration.
- Use local knowledge to inform parents where to find local information on direct payments, support brokers, transition, etc.

Key messages

- My friends and family are my friends and family – they are not my PA.
- Explorations of independence v interdependence.
- Building aspiration.
- Inclusive education = included life.
- Direct payments, support brokers, transition.

Inclusive Education

Inclusive education enables all students to fully participate in any mainstream early years provision, school, college or university. Inclusive education provision has training and resources aimed at fostering every student's equality and participation in all aspects of the life of the learning community.

Inclusive education aims to equip all people with the skills needed to build inclusive communities.

Inclusive education is based on eight principles:

- A person's worth is independent of their abilities or achievements.
- Every human being is able to feel and think.
- Every human being has a right to communicate and be heard.
- All human beings need each other.
- Real education can only happen in the context of real relationships.
- All people need support and friendship from people their own age.
- Progress for all learners is achieved by building on things people can do rather than what they can't.
- Diversity brings strength to all living systems.

3.1 Activity 11: What is a good life?

Aims

- This activity aims to help parents think about and start planning for the kind of life they want their child to live (and what their child wants too).
- Use the following questions to help parents plan a positive future for their child individually.
- Encourage those that want to share their plan.

Key messages

- Parents need time and support to be able to think about and plan the kind of life they want for their child.
- Parents need to see from the example of Disabled adults the kind of life that is possible for their children.
- Disabled children are no different from other children and want the same things.
- Listening to your child is essential in this process.
- Intentional planning and the identification of allies is key to success.
- Nothing about us without us.

What is a Good Life?
Planning Positive Futures

- What kind of life would you like your child to have?
- What are your child’s wishes and dreams?
- How does your child view the situation?
- What do you love about your child?
- What do others love about their child?
- What needs to happen to build that life?
- Think about, and write down next steps, key milestones, final outcome (your child as an adult living life).
- What’s happening around you - where are your friends, family and allies?
- Who can help your child?
- What support do you need?
- Identify and commit to the first step (this is the first action on your child’s plan).

3.1 Activity 12: You can, I can, WE can

Aims

- This activity aims to explore the different expertise and experiences that Disabled adults/ young people and parents have, and to support them to identify what experience is unique to Disabled adults, what experience is unique to parents. Additionally, this activity aims to explore what experiences and expertise Disabled adults and parents share; and what things neither Disabled adults nor parents know and may have to find out from others.
- It aims to lay the foundation for planning ways Disabled adults and parents can work together, eg on a campaign, on a social action project or on making the functions of the DPO more accessible and targeted towards Disabled young people.

Key messages

- It is really important for Disabled adults, Disabled young people and parents to work together.
- This is because Disabled adults know or have experienced things Disabled young people and parents have not – but Disabled young people and parents also know or have experienced things Disabled adults have not.
- There are also many things that Disabled adults, Disabled young people and parents have in common.
- It is important for Disabled adults, Disabled young people, and parents to work together to make DPOs more accessible to Disabled young people and parents.

3.1 Activity 12 (cont.): You can, I can, WE can

The Activity

Requirements:

- Large sheet of paper or flipchart paper
- Post-it notes

1. On the large piece of paper, draw a large box with 6 quadrants (see following page).
2. Either in small groups or in the whole group, ask everyone (adults and young people) to suggest things to write into each box. People can write or draw these on the paper or onto post-it notes they can then stick onto the right box.
3. The first box (top left) is for things only Disabled adults know or have experienced (and that Disabled young people haven't experienced) eg employing your own PAs.
4. In the 2nd box (top centre), add things only Disabled young people know or have experienced eg what it's like being a Disabled teenager nowadays. The 3rd box is for parents.
5. In the 4th box (bottom left), add things both Disabled adults, Disabled young people and parents know or have experienced, eg experiencing discrimination or certain barriers.
6. In the 5th box (bottom right) add things neither Disabled adults nor Disabled young people or parents know or have experienced eg what its like to live in a fully inclusive/barrier free world.
7. Once there are ideas in each box, discuss as a group the different things Disabled adults and Disabled young people know and can bring to working together, things they both have in common, and things no one knows!

(cont.) 3.1 Activity 12: You can, I can, WE can

What experience or knowledge do only Disabled adults have?

(What things do Disabled adults know or have experience in that Disabled young people don't? / parents don't?)

What experience or knowledge do only Disabled young people have?

(What things do Disabled young people know or have experience in that Disabled adults don't? / parents don't?)

What experience or knowledge do only parents have?

(What things do parents know or have experience in that Disabled adults don't? / Disabled young people don't?

What experience or knowledge do we share or have in common?

(What things do both Disabled adults, Disabled young people and parents know or have experience in?)

How do we move forward together?

(How can we use all of our knowledge and skills to create change?)

Session 4

Partners in change – what now

- Who can help / what can you use or do?
- DPOs create/facilitate parent groups
- Partnership with Disabled young people
- Peer support
- Share resources
- Groups in schools
- Campaigning

4.1 Activity 13: How parents and DPOs can work together - who/what can help?

Aim

This activity aims to support DPOs and parents to plan projects to work on together. For example, these projects could be a local campaign, a social action project or a way of making an aspect of the DPO's work more accessible for parents.

Requirements:

- Large piece of paper
- Coloured pens
- Post-it notes

The Activity

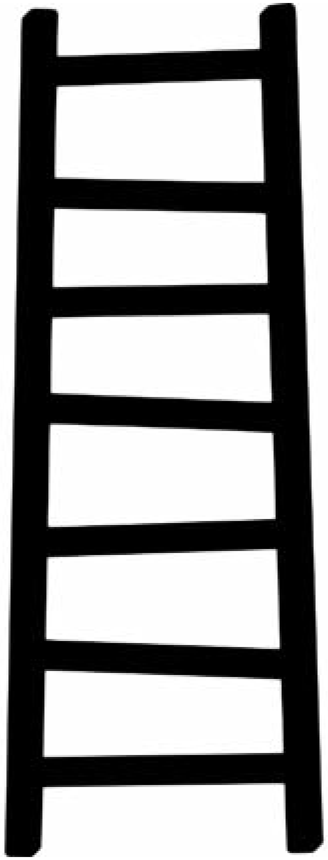
1. Stick a large piece of paper to the wall (eg 2 or 3 pieces of flipchart paper).
2. Draw a ladder that starts at the bottom of the paper and finishes near the top of the paper (you could also choose to draw a road instead of a ladder).
3. At the top of the ladder write the aim or goal of the project that you want to work on together eg to develop a youth forum at a DPO or make a DPO's advice service accessible to parents.
4. At the bottom of the ladder write 'Where we are now'.
5. In small groups or as a whole group discuss:
   - The aim or goal – what would this look like if the project was a success? How would we know we've done a good job? What would good look like? Write these on the paper.
   - Where we are now – what are the problems with how things are now? Why do we want to change things? Write these on the paper.

(cont.)

(cont.) 4.1 Activity 13: How parents and DPOs can work together

The activity (cont)

6. Brainstorm together to think of all the different ideas or things that need to happen to get to the goal. Write or draw these on post-it notes – try to be as specific as you can about what needs to happen and keep the steps small and manageable.
7. Once everyone has thought of all the different things that need to happen, start to put them in order by sticking the post-it notes to the rungs of the ladder, to show the different steps in planning the project. You could also think about who could do each step or task and by when.



Tip:

It might be helpful to do a pretend example first – eg we are organising a karaoke night – and work through the steps as a group.

- The aim or goal – what would this look like if the project was a success? How would we know we've done a good job? What would good look like? Write these on the paper.
- Where we are now – what are the problems with how things are now? Why do we want to change things? Write these on the paper.

Finally: Agree next steps/action plan and Evaluation

Aim

- To understand what has changed as a result of the training, what parents thought of the training, and what actions parents and DPOs have committed to.

Resources

- Time needed: 10-15 minutes
- In this toolkit: evaluation forms (see next page)
- Materials: post-it notes, sticky dots, pens
- Parents' contact details sheet

Parents as Allies – Have your say!

What was your favourite thing about the training?

What would you like to know more about?

What did you learn today?

What action/actions have you committed to today?

Which face best describes how you feel about the event?

☹	😕	😐	🙂	😀
☐	☐	☐	☐	☐

Appendix: Icebreaker 1

Requirements:

- Human Bingo cards: each square of the card has a different piece of information – up to four:
  - has curly hair;
  - has a pet;
  - has been on holiday to another country;
  - plays a sport;
  - has brown eyes;
  - is on Facebook;
  - is on Twitter;
  - has a birthday in December; etc
- Pens

Human Bingo

1. Everyone receives a bingo card.
2. The aim is to find one person who matches the information.
3. Each time you meet a new person you are only allowed to ask them one question then move on.
4. Players should move around the room asking each other one question at a time.
5. If someone asks you a question and the answer is yes, put your name or a cross on the person's card.
6. The first person who fills up their whole card first and shouts 'human bingo' wins.

Appendix: Icebreaker 2

Two Truths and One Lie

1. Ask participants to work in pairs (if it's a small group this activity could be done with everyone together and asking each person).
2. They have two minutes each to find out three pieces of information about their partner.
3. Two pieces of information will be the truth and one must be a lie.
4. Person A talks for two minutes then swap around so that Person B is talking.
5. After two minutes check that everyone remembers which are the truths and which is the lie.
6. Each person introduces their partner to the group, saying their name and the three things they have learned about their partner.
7. The rest of the group must guess which piece of information is the lie.
8. If the rest of the group doesn't guess the lie correctly the pair win a prize (we'll leave the choice of prize to you).

Appendix: Disability History Timeline

for Activity 3

- **1913 Mental Deficiency Act** required children and adults who were identified as 'defective' to be institutionalised.
- **1914–18 The First World War** created 20 million Disabled men across Europe.
- **1933 The Nazis came to power in Germany** and introduced compulsory sterilisation of Disabled people.
- **1939 The Nazi euthanasia programme** murdered 240,000 Disabled people.
- **1970 The Chronically Sick and Disabled Persons' Act** required local authorities to improve services for Disabled people.
- **1972 The Disability Rights Movement is born** - Paul Hunt's letter is published in the Guardian newspaper calling for equality for Disabled people and asking others to join him. His letter inspires the start of the struggle against discrimination.
- **1970s Disabled people created the 12 Pillars of Independent Living.**
- **1976 Union of Physically Impaired Against Segregation was set up**, the first organisation to argue for a 'Social Model of Disability'.
- **1978 UKDPC (formerly known as The British Council of Disabled People's Organisations) was set up** to campaign for Disabled people's rights (now no longer running).

Appendix: Disability History Timeline

- **1981 Disabled Peoples' International (DPI) and the International Year of Disabled Persons** was the world's first successful cross-disability Global Disabled People's Organisation (DPO), this led to the slogan "Nothing About Us Without Us".
- **1981 The Education Act** paved the way for the inclusion of Disabled children with 'special needs' during the United Nations International Year of Disabled People.
- **1990 Alliance for Inclusive Education** set up to campaign against segregated education.
- **1991 The UK Government ratified the UN Convention on the Rights of the Child** – very few references to Disabled children and young people but it did enshrine a human right to participate in decision making.
- **1995 The Disability Discrimination Act (DDA)** made discrimination against Disabled people illegal and was an important step forward in the campaign for full civil rights for all Disabled people (this took 17 attempts to introduce comprehensive and enforceable civil rights for Disabled people between 1982-1995).
- **1996 The Community Care (Direct Payments) Act** came into force, enabling local authorities to make cash payments to Disabled people for their support needs.
- **1996 National Centre for Independent Living** founded (it has now merged with Disability Rights UK).
- **2000 The Disability Rights Commission** was set up with Disabled people forming a majority of its commissioners (now no longer running).

Appendix: Disability History Timeline

- **2001 The Special Educational Needs and Disability Act** passed, a turning point for inclusive education.
- **2003 BSL recognised as an official language,** a milestone for the inclusion of Deaf people.
- **2008 Inclusion London** created to support Deaf and Disabled people's organisations in London and campaign for equality for Deaf and Disabled people.
- **2009 The UK Government ratifies the UN Convention on the Rights of Persons with Disabilities.**
- **2010 The Equality Act 2010** came into force legally protecting people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single act, making the law easier to understand and strengthening protection in some situations. It sets out the different ways in which it is unlawful to treat someone.
- **2010 UK Disability History Month** launched, creating a platform to focus on the history of our struggle for equality and human rights.
- **2011 Hardest Hit March** in London saw an estimated 8,000 people take to the streets protesting against austerity and the huge cuts to services it involved.
- **2012 Reclaiming our Futures Alliance** founded to defend Disabled people's rights and campaign for an inclusive society.

Appendix: Disability History Timeline

- **2014 The Children and Families Act** came into force on the 1st September 2014 changing SEN statements to Education, Health and Care (EHC) plans for Disabled children & young people 0–25 years.
- **2014 The Care Act** states that from April 2015 councils need to assign a personal budget to all people who are eligible for support. The personal budget is the amount of money needed to cover the cost of the support for which a person is eligible.
- **2015 The Independent Living Fund** closed, setting back Disabled people's right to Independent Living.
- **2016 UN** guidelines confirm governments must phase out segregated education under Article 24.
- **2017 Defiant Lives** film released, telling the story of the rise and fight of the Disabled people's rights movement in the US, UK and Australia.
- **2017 UNCRPD Committee publishes its Concluding Observations** based on the first monitoring of the UK Government's implementation of the UNCRPD. The Committee's findings are damning and conclude that the Government's current approach to Disabled people in the UK is causing a 'human catastrophe'. The Committee reminds the UK Government that inclusive education is 'not a choice, it is a human right'.
- **2018 Alternative Global Disability Summit** held in London to highlight the hypocrisy of the Global Disability Summit being co-hosted by the UK government.

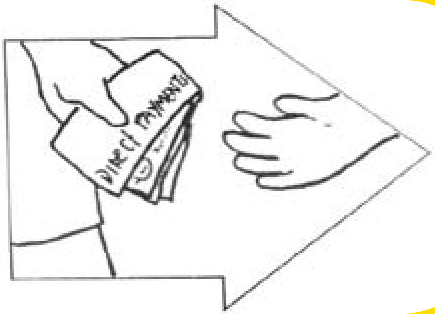
(1/4)

Appendix: What Disabled People Want

A guide for potential allies

Disabled people want to live valued lives in the real world with the support we need. To achieve this we need:

Personal assistants to help us live and do the things we want in ordinary homes, schools and communities.



Money to pay them ourselves, or through a self-appointed advocate (or our parents when we are very young)

A well-funded Independent Living Centre in every local authority area, run by disabled people.

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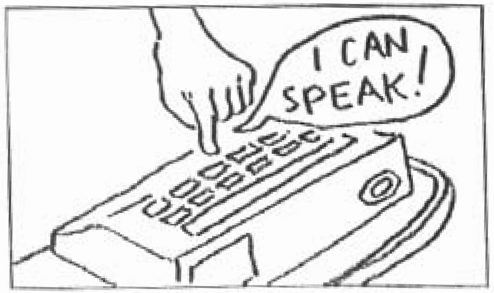
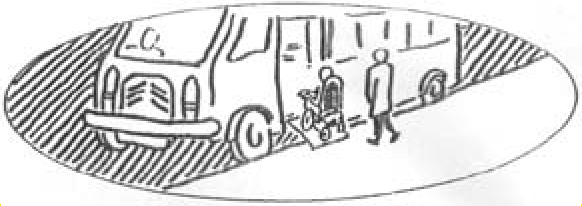
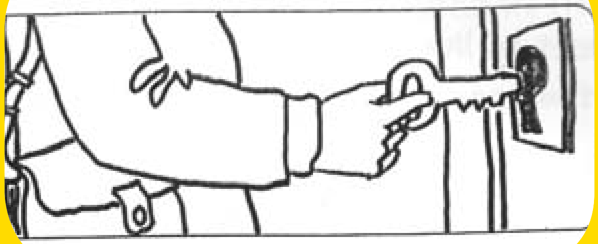


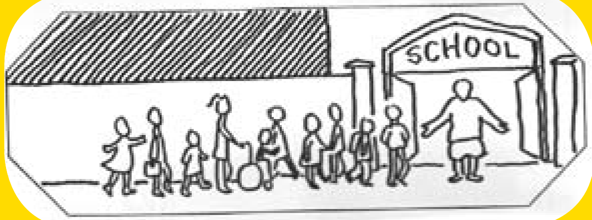


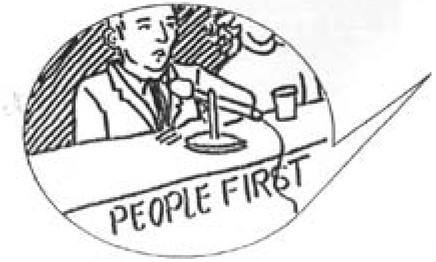


Technological aids when we need them, even if they cost a lot...

Accessible and affordable public transport

Accessible and affordable housing





Accessible information

Inclusive education, in order to make friends and learn how to live together in the world

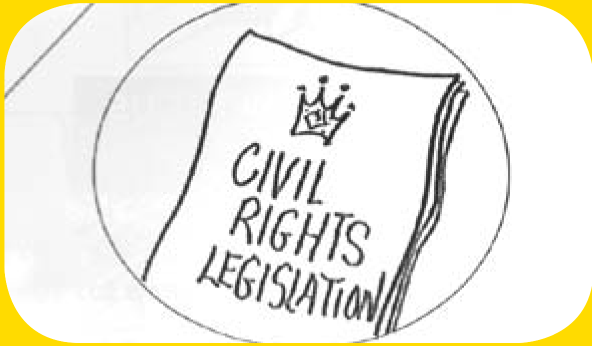
To speak for ourselves individually and through our own organisations

The recognition of the national sign languages of Deaf persons as official languages

Real jobs for real wages, with support if necessary

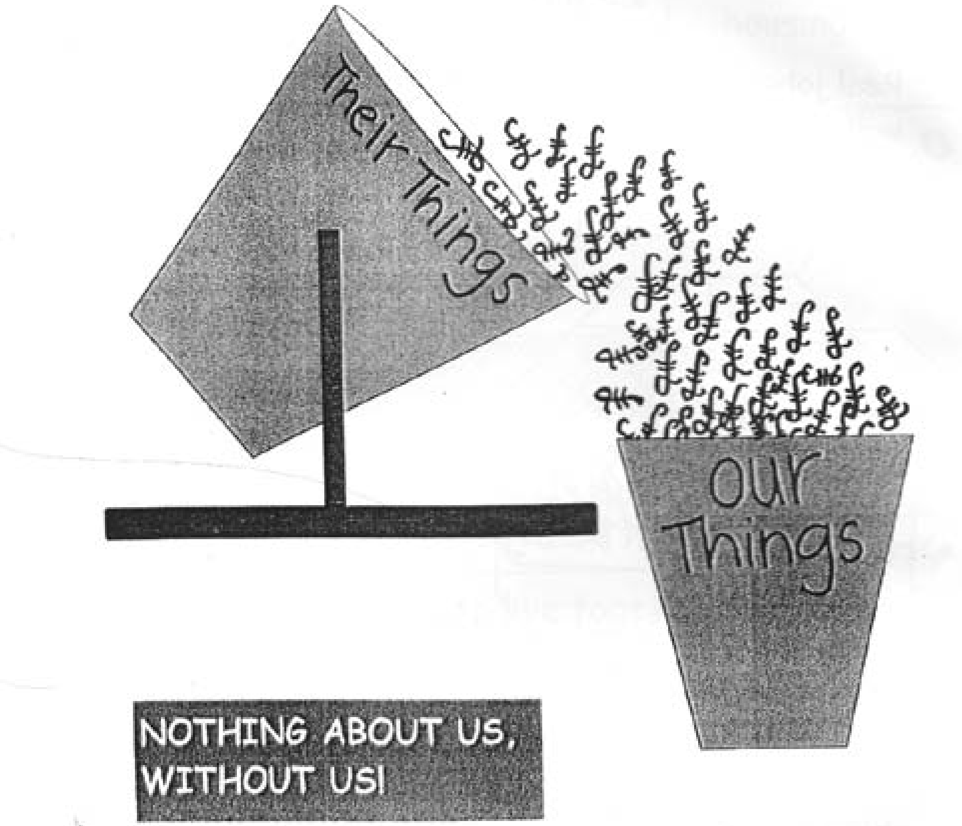
Ordinary places designed so that everyone can use them

Protection in law against discrimination and cruelty



A massive

Transfer of resources from segregated provision and organisations ‘for’ Disabled people, to all the things we have described in this toolkit



Glossary

- A Disabled People's Organisation (DPO) is an organisation which collectively represents Disabled people and works in solidarity for the right to equal access of all Disabled people to services, justice, family life, right to life in the community, employment, education and so on.

Useful Resources

- Get your rights (health emphasis): www.getyourrights.org/right/making-decisions/
- Your rights, your future: Training for young people (education emphasis): www.councilfordisabledchildren.org.uk/making-ourselves-heard/resources/your-rights-your-future-toolkit
- Council for Disabled Children decision-making toolkit (general): www.councilfordisabledchildren.org.uk/help-resources/resources/decision-making-toolkit-0