



Supporting People with a Learning Disability to live Healthy, Safe and Fulfilled Lives

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Crossbench member, House of Lords

***Healthy, Safe
and Fulfilled
Lives***

Health and well-being

Health is made at home

- *Hospitals just fix things*

Think healthy lives

Better lives mean better health

We look after our money

**Let's look after our mental
wealth too**



My Report:
*My Heart
Breaks*

What went
wrong?



WHAT ARE THE
ANSWERS?

- Things are still going wrong

Crisis responses
Institutional
culture
Social factors
forgotten

WHAT ARE THE ANSWERS?

Support MUST BE:

- relational and personal
- family based

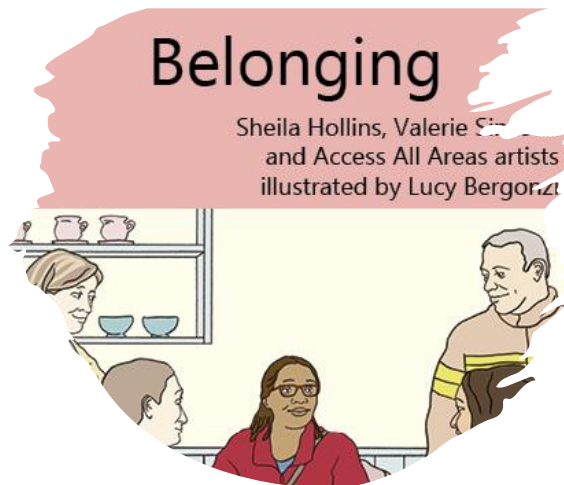
Small supports work best

Make reasonable adjustments

Our brief today:

How to live healthy, safe and fulfilled lives

Answers
include social
prescribing



The BELONG
manifesto
An Ordinary Life

Book clubs

BELONG manifesto

B
E
L
O
N
G

Be active and be healthy – like eating well, dancing, swimming and joining in.

Entertain our friends and family and show them we care.

Love ourselves...and welcome the love and support of others. And if things go wrong say yes to help.

Ordinary things – like choosing where we live, and what we do and share.

New things to make our lives more interesting – like drama, drawing, singing and sharing stories – with the support we need.

Give something nice – like our time, our work, a hug... every day.



Belonging
Sheila Hollins, Valerie S...
and Access All Areas artists
illustrated by Lucy Bergorzi

B Be active and be healthy - like eating well, dancing, swimming and joining in.

E Enjoy our friends and family and show them we care.

L Love ourselves...and welcome the love and support of others. And if things go wrong say yes to help.

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[AAATheatre www.accessallareastheatre.org](https://www.accessallareastheatre.org)
[@uk_beyondwords www.booksbeyondwords.co.uk](https://www.booksbeyondwords.co.uk)

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ACCESS ALL AREAS **MADHOUSE re:exit** **Beyond Words**
empowering people through pictures

A living manifesto for a better life for people with learning disabilities

When the institutionalisation of people with learning disabilities has ended...

- and there is enough money to spend on food and essentials,
- and there are opportunities to make some choices in life
- and people with learning disabilities feel good about themselves and their friends
- and there is an end to being bullied, assaulted and called names
- and everyone can access healthcare, education and employment, on equal terms

We will all **BELONG**

Six ways we can be sure of feeling good about ourselves and our friends:

B Be active and be healthy - like eating well, dancing, swimming and joining in.

E Enjoy our friends and family and show them we care.

L Love ourselves...and welcome the love and support of others. And if things go wrong say yes to help.

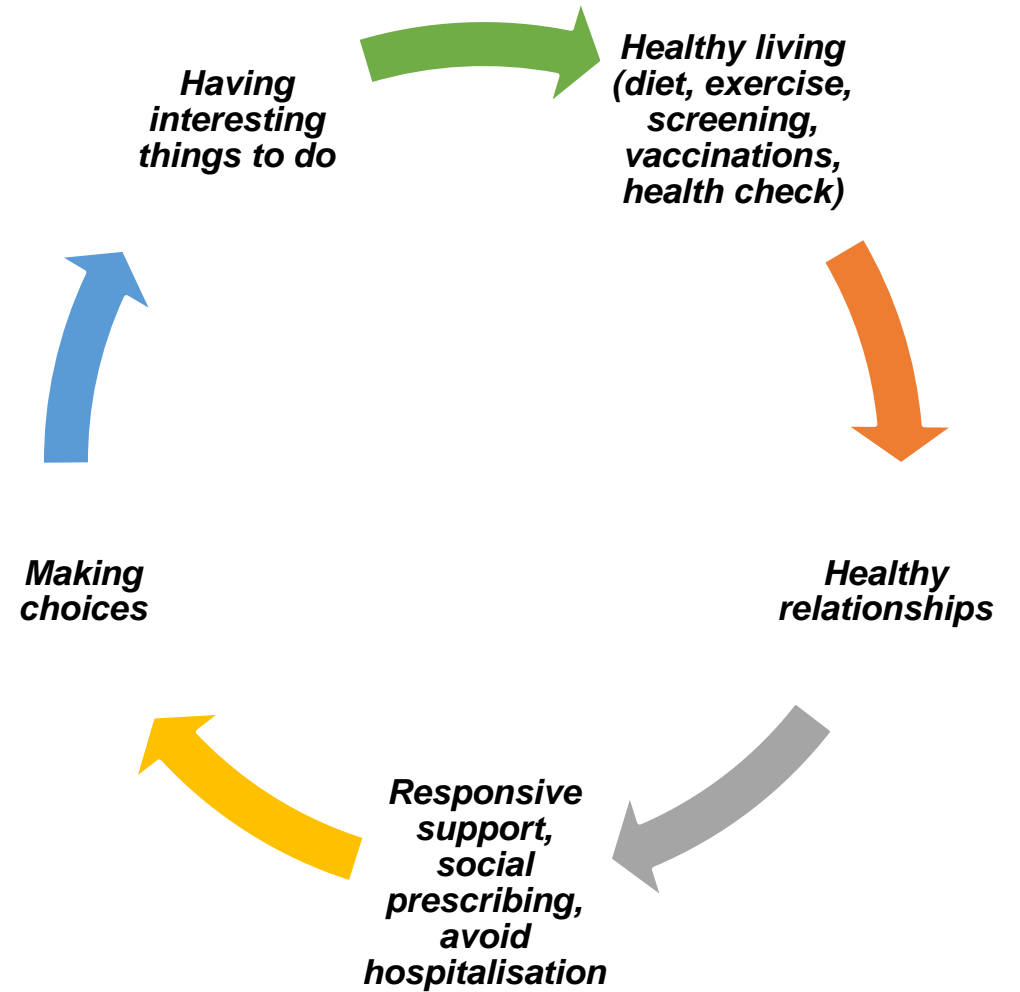
O Ordinary things like choosing where we live, and what we do and share.

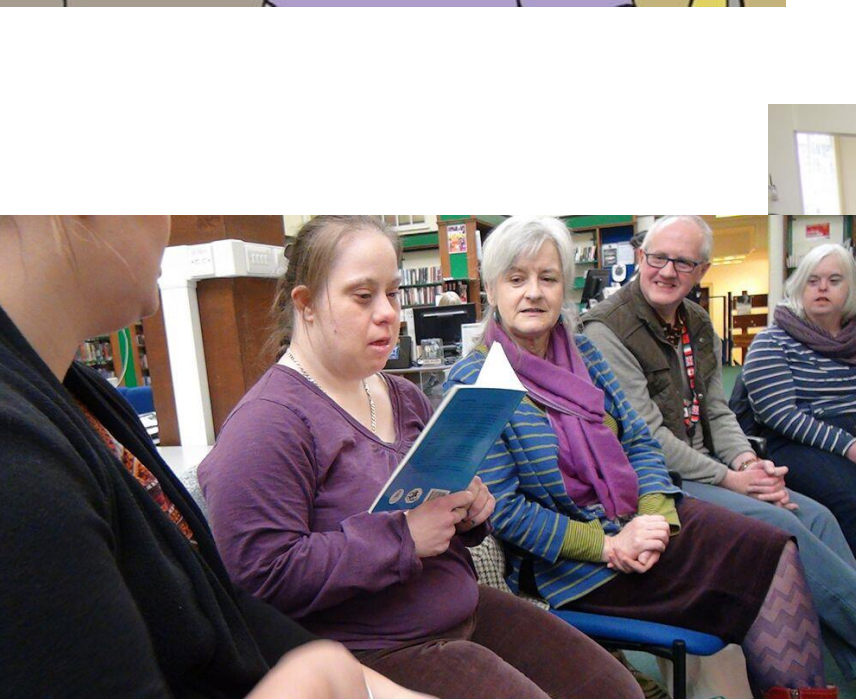
N New things to make our lives more interesting - like drama, drawing, singing and sharing stories - with the support we need.

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Prescribe:

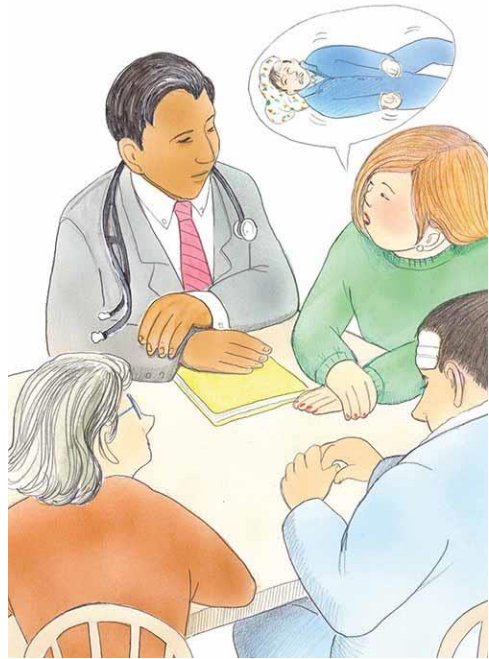
- ***a book***
- ***a book club***
- ***a healthy living group***



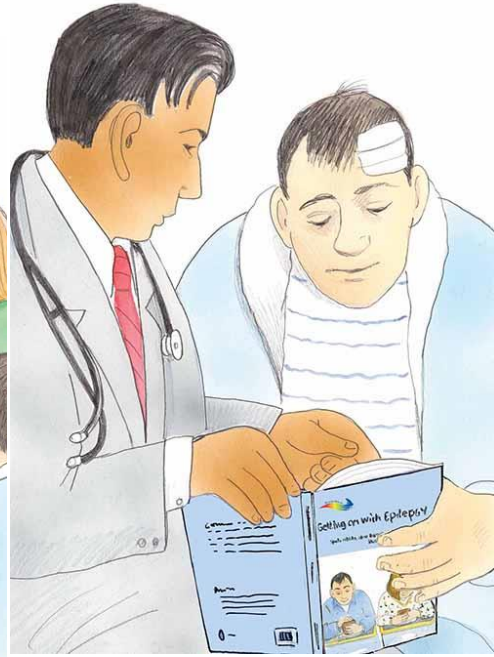


Beyond Words stories help people lead healthy, safe and fulfilled lives:

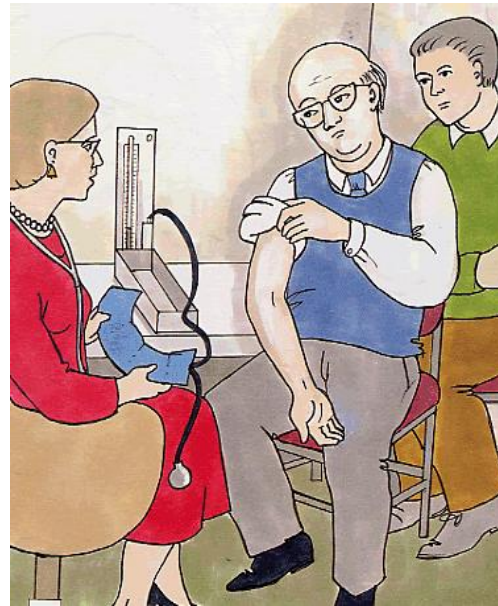
Check understanding



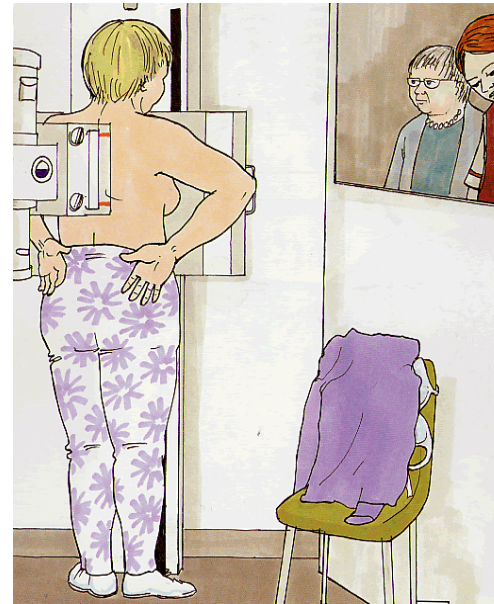
Support compliance



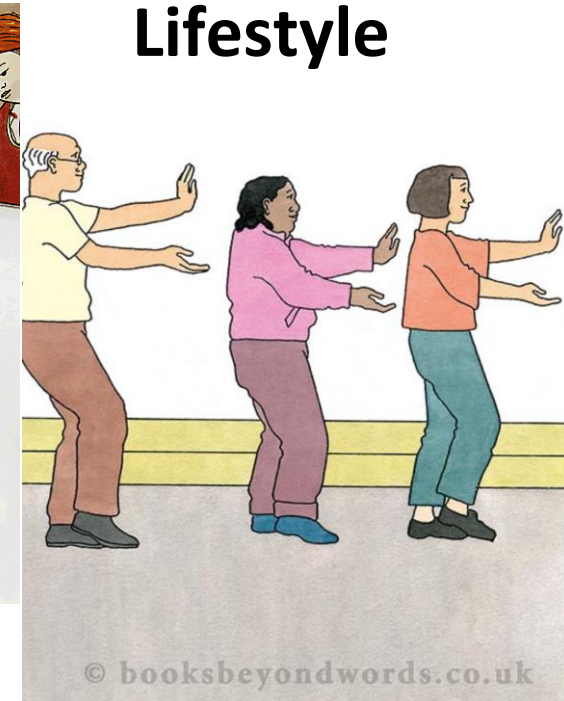
Share test results



Encourage screening



Support a healthy Lifestyle



People and their supporters often struggle to explain their symptoms

The evidence for pictures

- Hibbing and Rankin-Erickson's review of literature (2003) found that pictures helped:
- **To decode words**
- **To activate background knowledge**
- **To reflect and make predictions about what might happen.**



Compare word free with an Easy Read leaflet

- see www.easyhealth.org



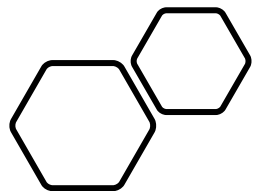
NHS

**Have you seen blood in
your pee, even once?**

Then it is time to tell your doctor.

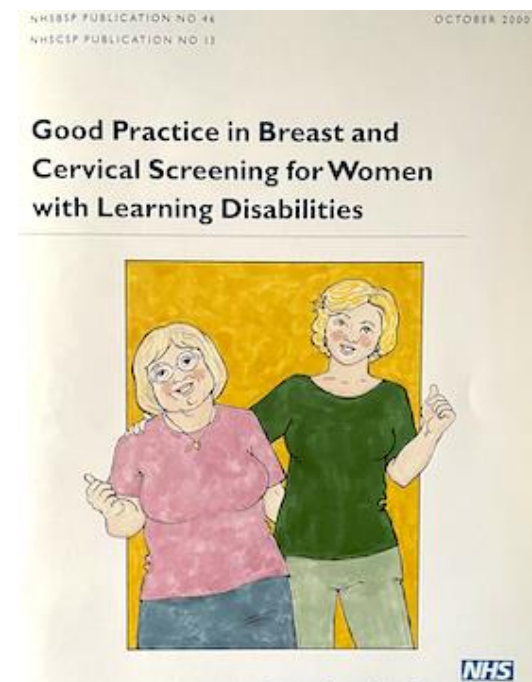
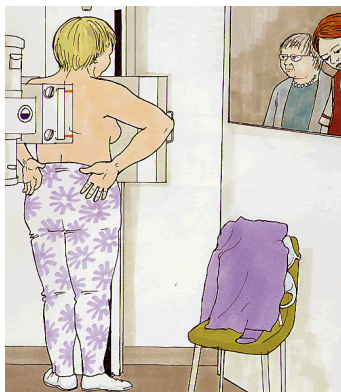
EasyRead version

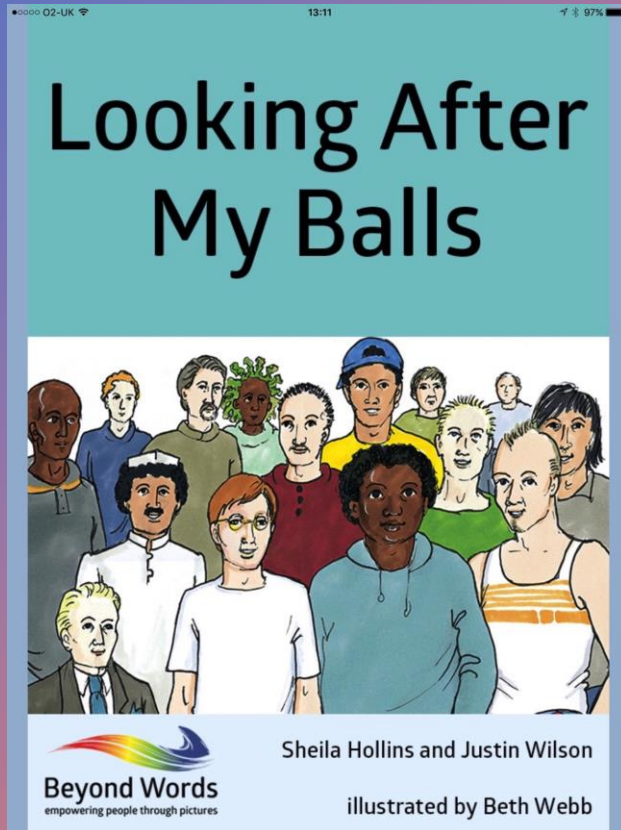
**BE CLEAR
ON CANCER**



Screening uptake by people with learning disabilities remains poor

- What progress has been made since Good Practice Guidance published in 2000?
- Have GP learning disability registers helped?





Testicular Cancer Screening Study

- 37 randomised to a Pictorial leaflet group
- 36 randomised to a **teaching group**
- **age of participants**
 - **16 to 35 years**

Compared confidence in self checking and seeking help

- Significantly improved confidence in ability to check and seek help:
 - initially by Teaching group participants
 - after six months also by those in the Leaflet group.
- 73% of the Teaching group and 61% of the Leaflet group reported testicular self-examination during the 6 months after the intervention.

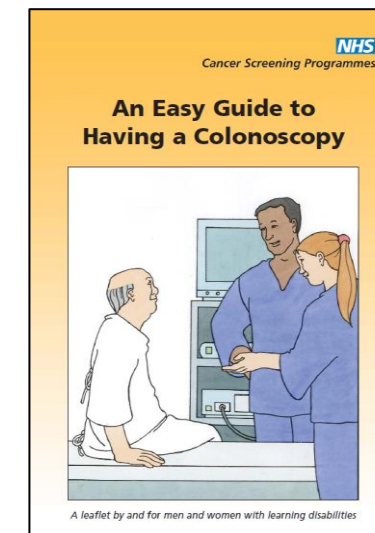
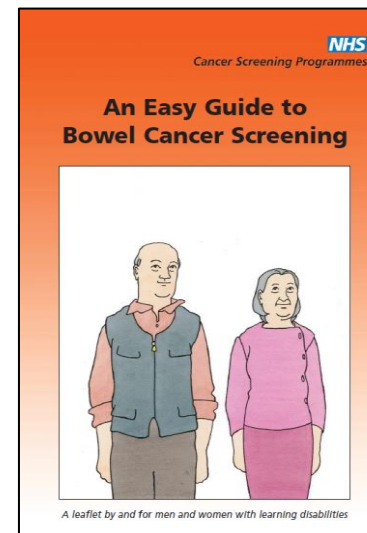
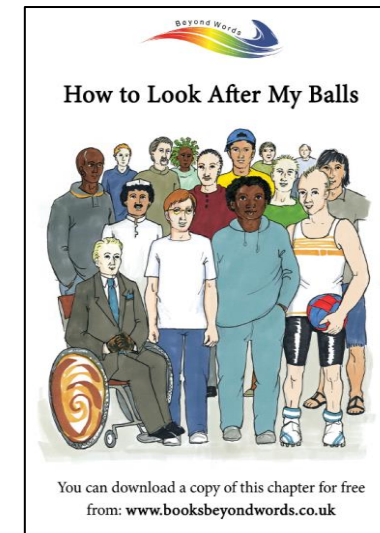
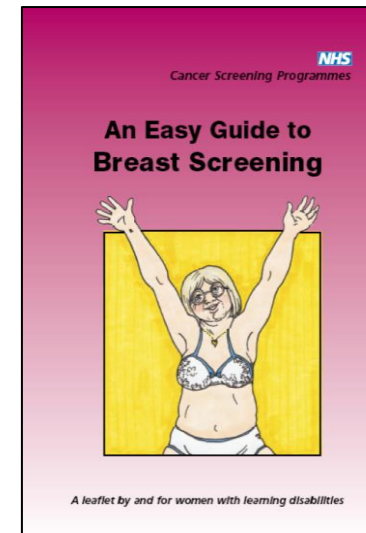
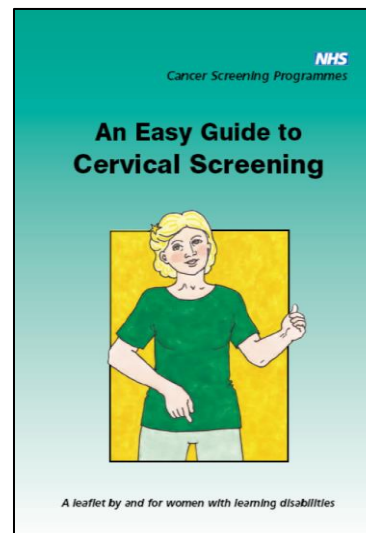
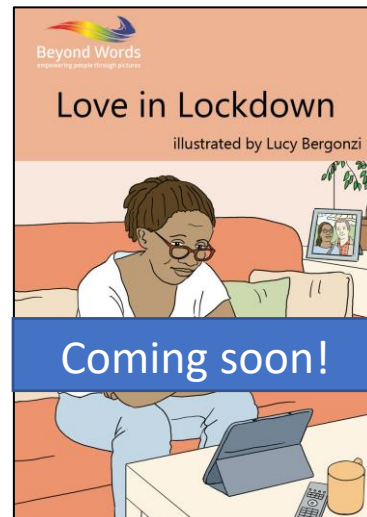
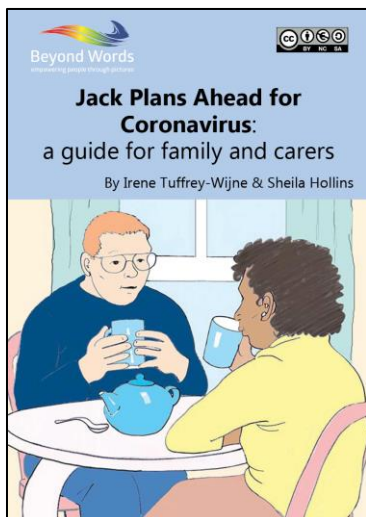
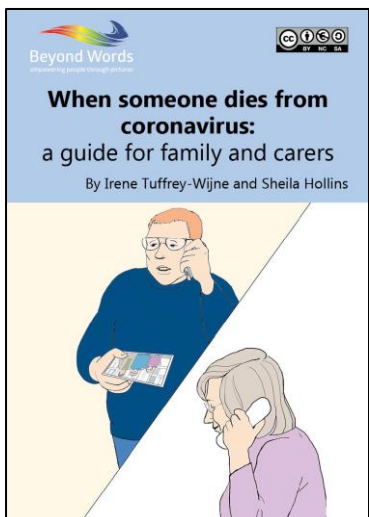
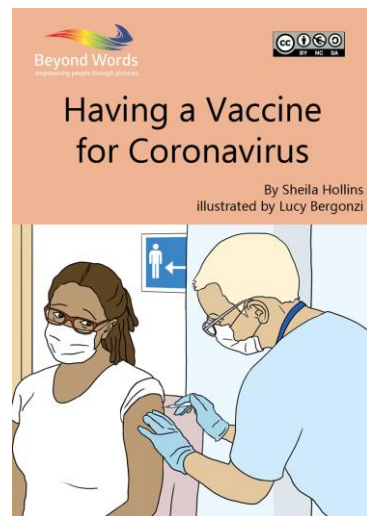
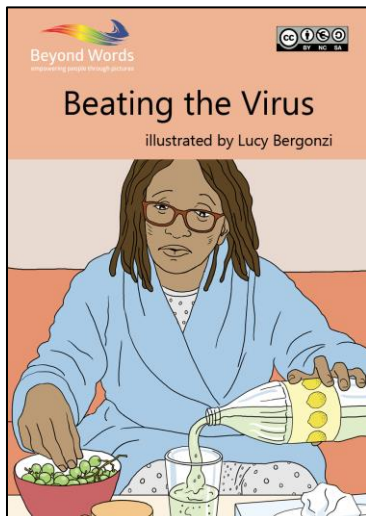
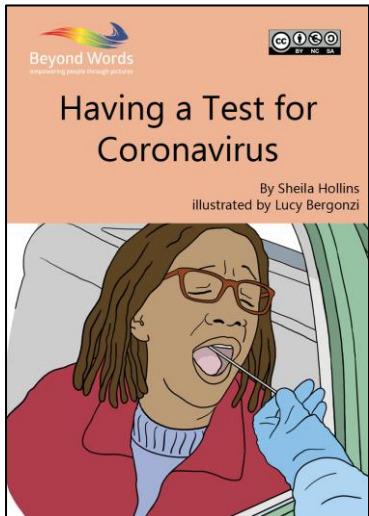


Tom learns how to check his balls



Free resources to support people through the coronavirus pandemic:

www.booksbeyondwords.co.uk/coping-with-coronavirus



Download free screening leaflets from:
www.booksbeyondwords.co.uk/resources-dl





The Oliver McGowan Mandatory training for health and social care professionals became law in July

Oliver died prematurely. His parents ask you to:

- Understand the Mental Capacity Act, Autism Act, the Human Rights Act, Equality Act.
- Put people at the heart of decision making.
- Respect their point of view.
- Do not make decisions without them.
- Explain well

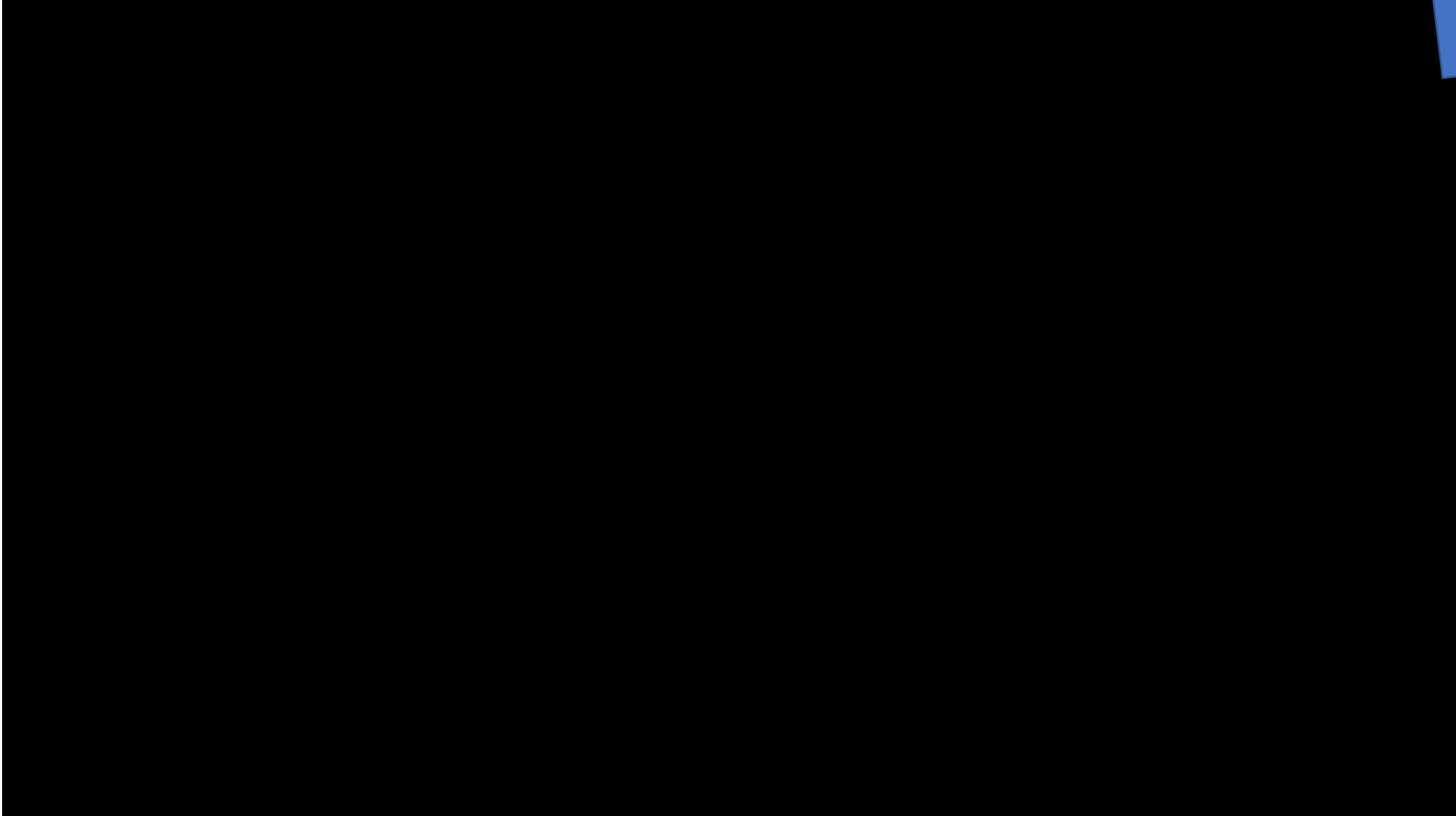


Gary Butler
Author and adviser

Involving experts by experience

- People with learning disabilities must be involved throughout the development, training and delivery of services

Involving experts by experience



Pictures used today are from the BWStoryApp

<https://booksbeyondwords.co.uk>

Many people **understand pictures better** than words

Quickly find a relevant health or social word free story in the BWStoryApp

BW Story App



visit:
www.booksbeyondwords.co.uk



The Beyond Words approach helps:

- To develop clinician skills and empathy
- To provide reasonable adjustments both at assessment and in treatment
- To focus on the relational aspects of the clinician/patient encounter

Tuffrey 2013, 2014; Riess 2014; Sanghavi 2006; Baum et al 2011,

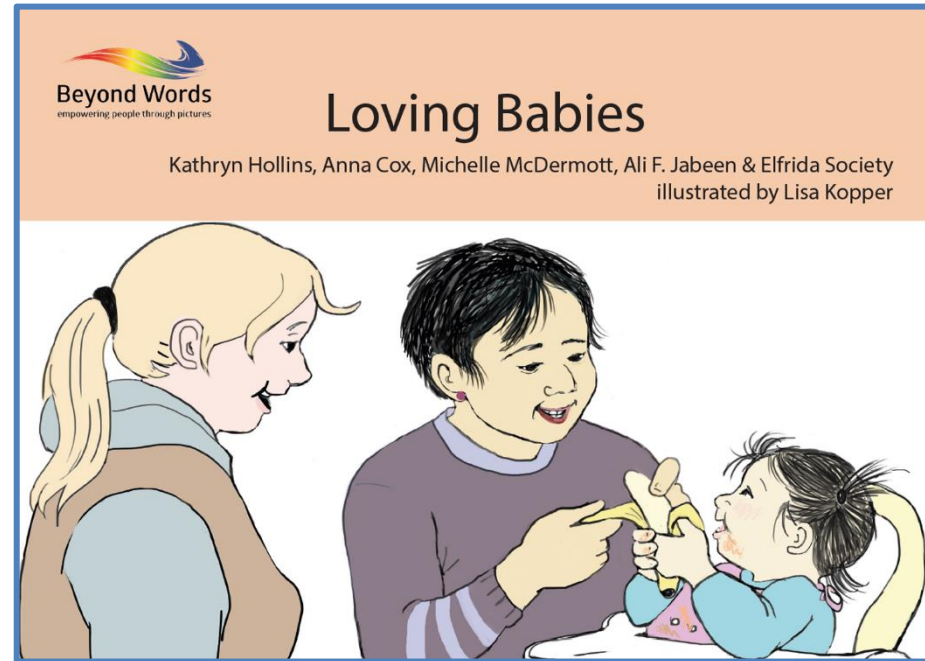
Hassiotis et al 2012

Picture stories to enrich the lives of the people you care about

Read more here:

1. Hollins, S., Egerton, J. and Carpenter, B. (2017), Using wordless books to support clinical consultations *Journal of Mental Health Training, Education and Practice*. Emerald. DOI: <http://dx.doi.org/10.1108/jmhtep-03-2017-0022>)
2. Hurtado, B., Jones, L. and Burniston, F. (2014), “Is Easy Read information really easier to read?”, *Journal of Intellectual Disability Research*, Vol. 58 No. 9, pp. 822–829.
3. Mengoni, S.E., Gates, B., Parkes, G., Wellsted, D., Barton, G., Ring, H., Khoo, M.E., Monji-Patel, D., Friedli, K., Zia, A., Irvine, L. and Durand, M.-A. (2016) “Wordless intervention for people with epilepsy and learning disabilities (WIELD)”, *BMJ Open*, Vol. 6 (Available at: <http://bmjopen.bmj.com/content/bmjopen/6/11/e012993.full.pdf>; accessed: 25.3.17)
4. Nikolajeva, M. (2012), “Reading other people’s minds through word and image”, *Children’s Literature in Education*, Vol. 43 No. 3, pp. 273–291.
5. Schlochtermeyer, L.H., Kuchinke, L., Pehrs, C., Urton, K., Kappelhoff, H. and Jacobs, A.M. (2013), “Emotional picture and word processing”, *PLoS ONE*, Vol. 8 No. 2, pp. e55619. (Online at: <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0055619>; accessed: 26.3.17)
6. Hastings, R., Durand, M. and Begum, S. (2016), *The Books Beyond Words Manual for Professionals, Trainers, Researchers and Funders*, Books Beyond Words and University of Warwick, London. Available from: Beyond Words CIO.

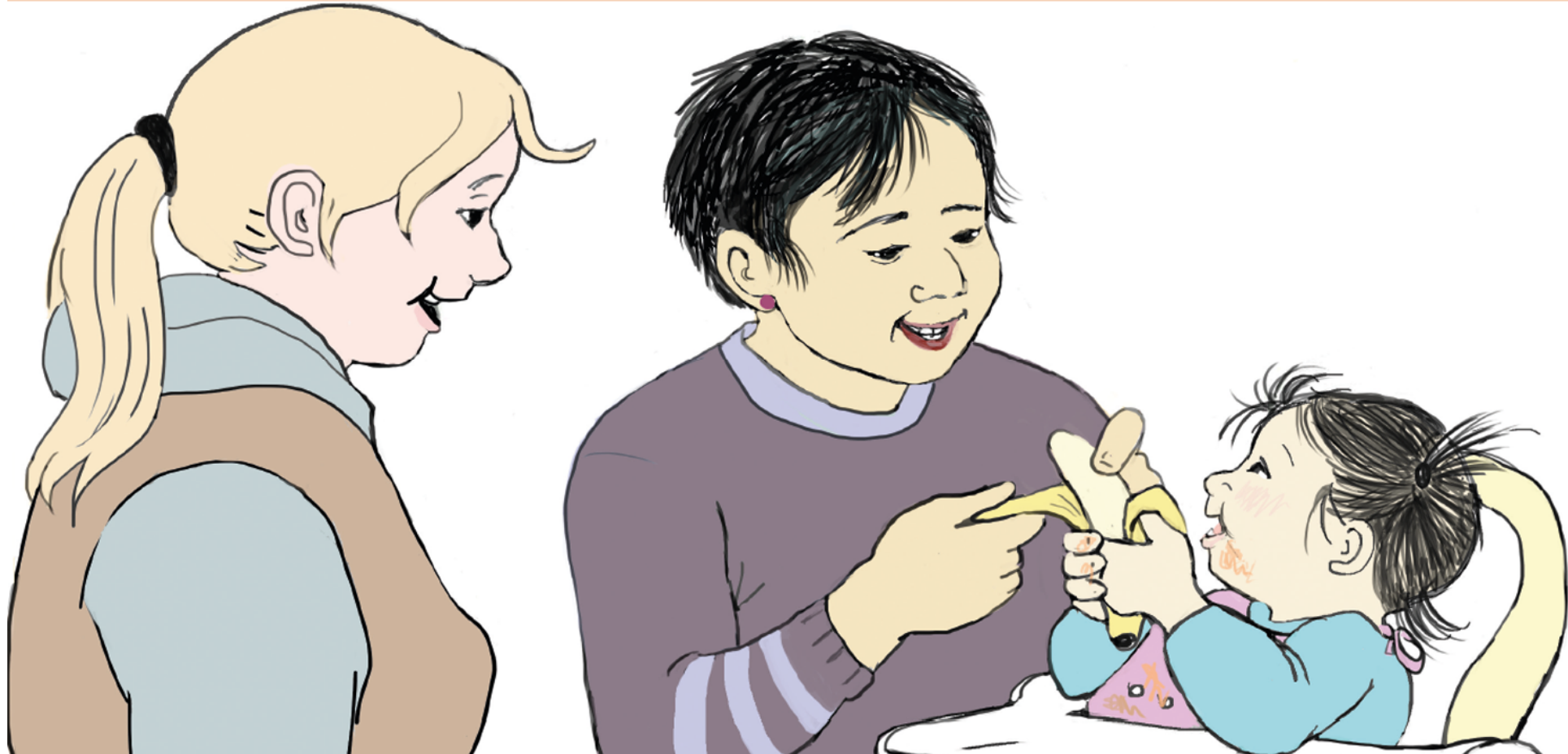
Book Launch





Loving Babies

Kathryn Hollins, Anna Cox, Michelle McDermott, Ali F. Jabeen & Elfrida Society
illustrated by Lisa Kopper



Why is this book needed?

- Parents with learning disabilities are more likely to have interactions with child protection agencies than with peer support groups.
- We want to send parents the message “you can”, not “you can’t”.
- Mothers with learning disabilities have equal rights to access maternity care as their peers but they often have poorer outcomes.¹
- Clear information is crucial, and pictures can be more easily understood than words by many people.

1. Malouf R, McLeish J, Ryan S, et al. ‘We both just wanted to be normal parents’: a qualitative study of the experience of maternity care for women with learning disability. *BMJ Open* 2017;7: e015526. doi:10.1136/bmjopen-2016-015526

How did we make it?

- Beyond Words, health and care experts and a professional artist worked together with parents with learning disabilities and their supporters to **co-create this book**.
- It took nearly **2 years to produce**: we got feedback on the pictures at each stage, making changes to images where the key message wasn't clear.
- As well as the pictures, we produce guidance and **recommended resources**, accessible via a QR code at the back of the book.

How we hope it will be used

- To **empower** adults with learning disabilities to access the support they need to become confident parents.
- To **open up conversations** about pregnancy and parenthood.
 - Checking **understanding**,
 - Supporting **decision making**,
 - **Sharing** experiences,
 - Exploring **feelings**.
- To benefit the **health and wellbeing** of the whole family.
- To **reduce the inequality** of rights for people with learning disabilities.
- To enable children to learn about **how relationships develop** between parents and babies.

Thank you to everyone involved

Artist: Lisa Kopper

Authors: Kathryn Hollins, Anna Cox, Michelle McDermott, Ali F Jabeen and the Elfrida Society Parents' Project.

Editor: Sheila Hollins

Book Coordinator: Laura Cook

Self-advocate Advisors: Areama Ford, Abdou Newland, Alexis Quinn, Charlotte Connery and Richard Lawrence.

Join us to read the book during the lunch break



booksbeyondwords.co.uk

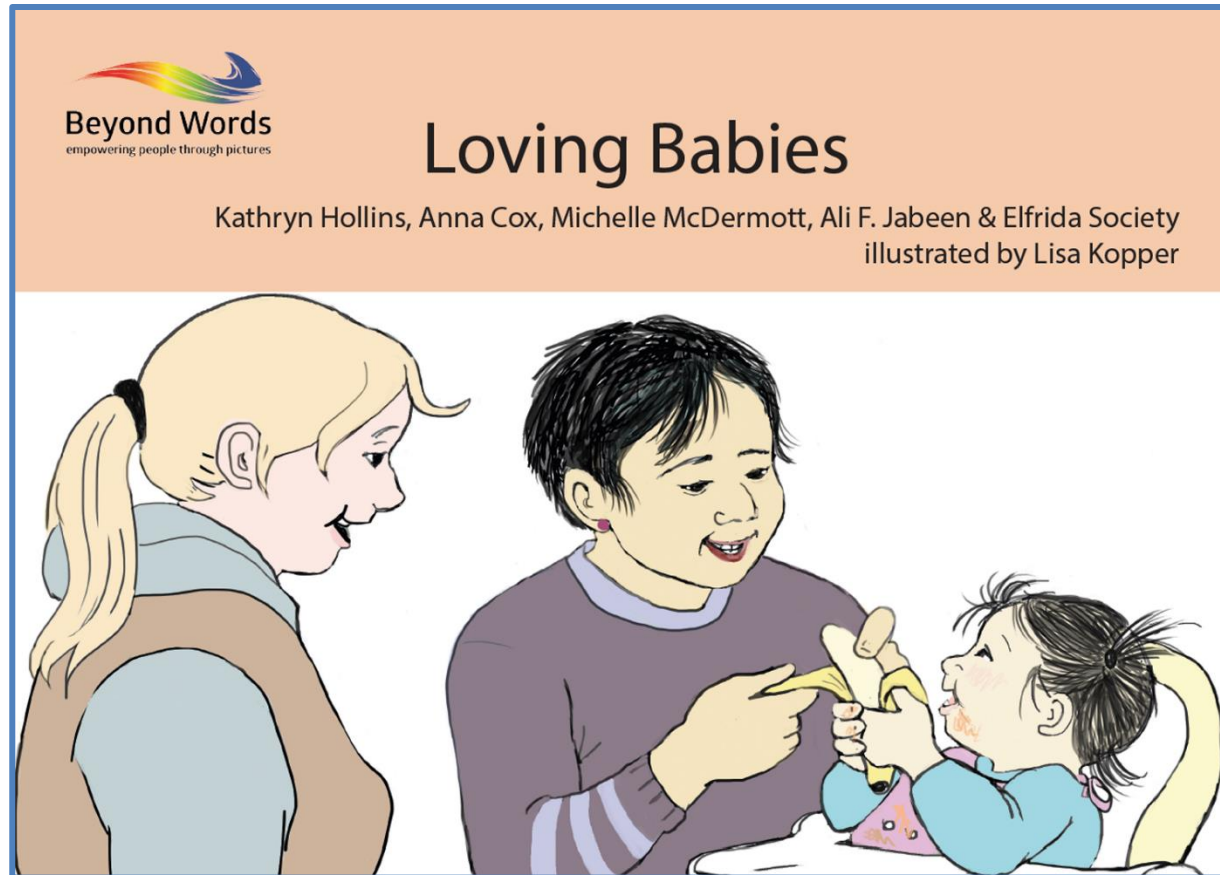


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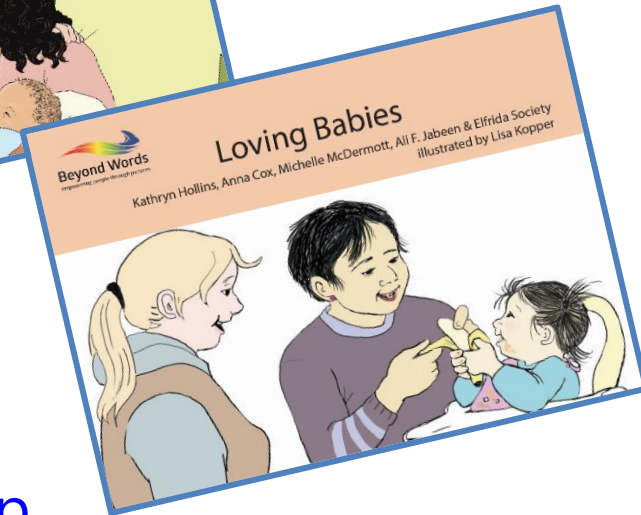


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