



**BUILDING A**

# **UK/JAPAN NETWORK**

**ON LEARNING DISABILITY  
AND BELONGING**

Reflections from an inclusive international exchange

by Liz Tilley, Hiromi Moriguchi, Ian Davies, Liz Ellis, Sara Ryan, Jan Sunman,  
Jan Walmsley, Marin Fujino, Chie Kasahara, Azusa Omori, Shun Omori, Hiromi Tanaka

# PLAIN ENGLISH SUMMARY

In 2019 a Japanese team met a UK team to learn about the lives of people with learning disabilities in each other's countries.

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Each team had researchers, a family member and a self advocate

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The Japan team visited London, Oxford and Milton Keynes in the UK

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The UK team visited Osaka, Hyogo and Nara in Japan

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We all learned a lot

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Working together in teams make a real difference

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Families in both countries want more choice and opportunities, good support, plans for the future when parents get older

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Belonging means different things to people from different countries

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Life stories help us understand what it means to belong



Our project helped us learn about brilliant things in both countries

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In the UK there are many strong self-advocacy groups

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In Japan there are businesses which employ people with learning disabilities as artists and in cafes

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In the UK people with learning disabilities have recorded their life stories

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In Japan many more people with learning disabilities have a paid job

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In the UK there are opportunities to do inclusive research

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In Japan people with learning disabilities have more generous pensions and benefits than in the UK

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We also learned that there are some things that need to change in both countries

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We will carry on working together

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We will share what we have learned





## INTRODUCTION

In 2019 we received funding to build a new research network between the UK and Japan. Our aim was to:

- Share what we know about the lives of people with learning disabilities and family carers in the UK and Japan;
- Talk to people with learning disabilities and family carers about 'belonging';
- Learn more about how self-advocacy and family advocacy works in the UK and Japan;
- Discuss how inclusive research can help us understand more about people's lives in different countries.

The network teams included people with learning disabilities, family carers and academics from the UK and Japan.

We built our network over two 'research exchanges' in 2019, each lasting 5 days.

We continue to be in regular contact by email.

# MEET THE TEAMS

## THE UK TEAM



**IAN DAVIES**

Self-advocate and founding member of Northamptonshire People First



**LIZ ELLIS**

Researcher at the University of the Highlands and Islands



**SARA RYAN**

Parent advocate and researcher at the University of Oxford



**JAN SUNMAN**

Parent advocate and founding member of the Oxfordshire Family Support Network



**LIZ TILLEY**

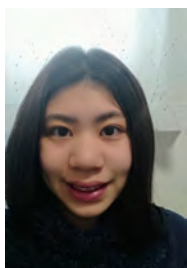
Researcher at the Open University, Chair of the Social History of Learning Disability Group



**JAN WALMSLEY**

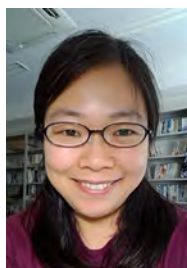
Researcher at the Open University, founder of the Social History of Learning Disability Group

## THE JAPAN TEAM



**MARIN FUJINO**

Advocate for her brother and PhD researcher at Doshisha University



**CHIE KASAHARA**

Researcher at Sophia University



**HIROMI MORIGUCHI**

Researcher at Tenri University



**AZUSA OMORI**

Parent advocate and founder of i-LDK Super-College



**SHUN OMORI**

Self-advocate and member of i-LDK Super-College



**HIROMI TANAKA**

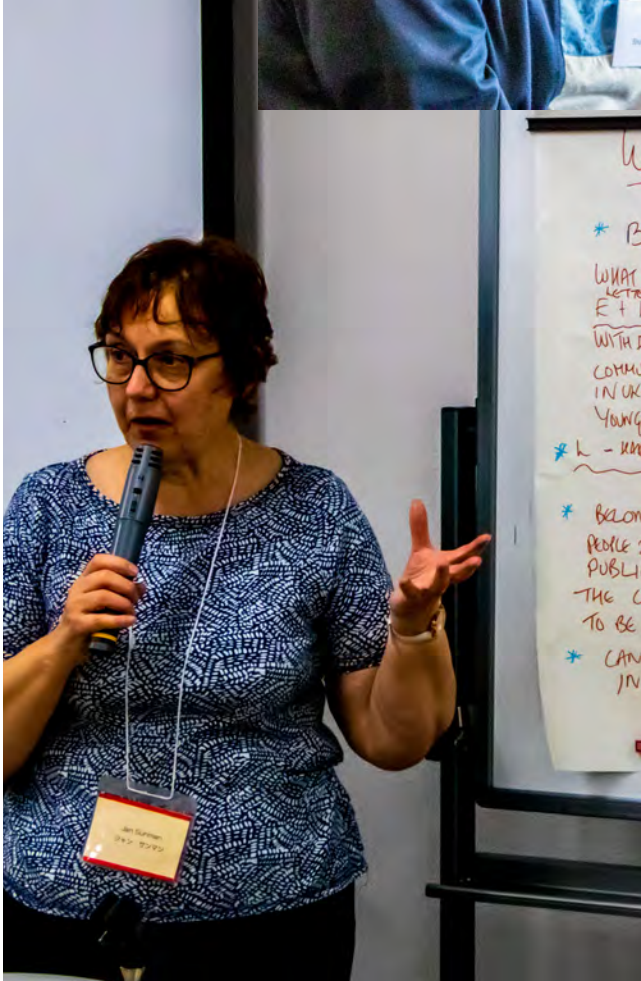
Researcher at Mukogawa Women's University

Many other people contributed to the project. We are very grateful for their support. Their names are at the end of the report.

# WHAT WE LEARNED DURING OUR PROJECT

This project was a unique opportunity to learn more about the lives of people with learning disabilities and their carers in two different countries and cultures.

We learned many things during our project. These are the things we thought were most important:



## UNDERSTANDING 'BELONGING'

Translating 'belonging' into Japanese was not easy. There is no direct translation.

The closest word is 'Shozoku', which means being a member of a group.

In Japan, it is important for people to feel part of a group (Shozoku). But this can sometimes bring negative feelings. Being part of a group might be limiting, or create social pressures. It can make someone feel that they cannot have a different type of life.

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The Japan team want to do further research to find out if it is possible for people with learning disabilities to move from 'Shozoku' to find a sense of belonging.

We learned that life stories can be a powerful way to help people to understand belonging. We saw this when Ian Davies presented his life story in Japan to social work students and to other people with learning disabilities.

In Japan and the UK, a key policy of the past two decades has been 'social inclusion'.

In practice, social inclusion has often focused too much on getting people into work, and has ignored other parts of people's lives.

We need to go back to the original vision for social inclusion. The idea of 'belonging' might help us do this.

People with learning disabilities must be at the centre of these discussions. We need to find better ways to support them to be involved, for example, through inclusive research.

## **What is the same and what is different for people with learning disabilities in Japan and the UK?**

We learned people with learning disabilities and carers in Japan do not have to fight so hard for their basic needs to be met.

Welfare provision in Japan is better resourced than in the UK and it is easier for people to access help if they need it.

More people with learning disabilities undertake paid work in Japan and this does not always affect their benefit entitlements.

However, not all the work for people with learning disabilities in Japan is 'good' work, and sometimes it is poorly paid.



Self-advocacy has not been very successful in Japan. This is possibly because:

- Western ideas about self-advocacy are often focused on the individual: 'speaking up for myself', 'exercising my rights', 'making my own decisions'. In Japan, it can be difficult for people to assert their own wants and needs. This is true for people with and without learning disabilities.
- There may be less reason to fight the system because people's basic needs are met in Japan. Self-advocacy often grows when people are desperate for change.
- We know that some people get involved in self-advocacy because it provides social connections and a 'reason to get up in morning'. Because more people with learning disabilities work in Japan, there may be less time (and motivation) to take part in self-advocacy activities.



The exchange inspired some people with learning disabilities, family carers and academics to think about the future role of self-advocacy in Japan.

In Japan, people with learning disabilities do not have many opportunities to continue with their education after secondary school. Colleagues in Japan think that further education might be a good way to promote self-advocacy. The i-LDK Super-College is one attempt to offer further education and support students to develop self-advocacy skills.



The UK team met family carers in Japan who want to make changes to give their relatives better lives. They often wanted similar things to families in the UK for their relatives:

- Choices about what they do
- Support that is safe and good
- Support for carers as they get older

We noticed that many of the problems for disabled Japanese people and their families in Japan were like remote rural areas of the UK:

- Both places have ageing populations of disabled and non-disabled people, so there are worries about who will support disabled people when their parents die.
- Getting people to work in health and social care is difficult which means services are limited. This means disabled people living in rural areas in Japan and the UK do not have much choice about the services they can access.

### **Learning from 'pockets of brilliance'**

- In both the UK and Japan, we saw some excellent practice: innovative, inspiring and compassionate.
- The UK team was very impressed by the work of Tanpopo-no-ye and the Good Job! Centre. The artwork was spectacular and unusual and demonstrated strengths and talents of people with learning disabilities. Sadly these are often overlooked or ignored.
- The Japan team was impressed by Yellow Submarine and the confident self-advocates they met from My Life My Choice.
- It made us wonder: how can we learn from what is good? What research methods can help us identify the 'pockets of brilliance', and build on them?

### **Doing international inclusive research**

- We learned that it is definitely possible to do it!
- It was important to have time to get to know each other and to have fun. This helped to build trust and confidence within our team.
- The inclusive teams were important to the success of the project. It is important to give people with learning disabilities and family carers opportunities to learn across cultures.
- The travel assistance programme we booked for Ian at the airport in Japan helped and supported the whole team. It meant we received a very warm welcome to Japan.
- We supported each other in different ways. In Japan, Shun made sure we were on the correct trains, at the right time. We would have been lost without him.
- We saw the power of inclusive research in action, and how it can help to build confidence and skills. Japanese colleagues commented that inclusive research could be a path to self-advocacy for some people.
- The role of our interpreters is vital. Taking time to prepare the interpreters in advance of meetings and seminars was very important.





## CONCLUSION

Even though our cultures are different, and we have different understandings about inclusion and belonging, we share many values such as the importance of meaningful employment and being creative.

Society in Japan is more communal than in the West, which may make self-advocacy more difficult, but the West can learn from Japan by thinking more about how we can be less about the individual and more about the community. Researchers and advocates from both countries can then identify and learn from each other's 'pockets of brilliance'.

# MORE INFORMATION ABOUT THE UK EXCHANGE

The UK exchange took place in September 2019. We met in London, Oxford and Milton Keynes.



## **SATURDAY 7TH AND SUNDAY 8TH SEPTEMBER: SIGHT-SEEING IN LONDON**

This gave us time to meet each other before we started our work. We spent the weekend in London getting to know each other, and having fun.

We had lunch in Borough Market, and walked along the Southbank to Tate Modern.

## MONDAY 9TH SEPTEMBER: OXFORD

We visited Yellow Submarine, a charity that supports people with learning disabilities and autism to live life to the full.

We heard about Yellow Submarine's work supporting young people into employment.

We ate delicious cakes made at the Yellow Submarine café, which is staffed by people with learning disabilities.



We then had a meeting in the Radcliffe Humanities Building, University of Oxford.

We listened to presentations from:

- Eddy McDowall, Chief Executive of Oxfordshire Association of Care Providers
- Chris Ingram (Chief Executive) and three ambassadors: Rachel Knapp, Daniel Orpin and Grace Kerrigan from Style Acre, a local service provider.
- Kathy Liddell a parent carer who works for Oxfordshire Family Support Network.

We learned about learning disability services in England and supported living arrangements in Oxfordshire.

We ended the day with a Guided Tour of the Oxford colleges, and dinner in a traditional Oxford pub.



## **TUESDAY 10TH & WEDNESDAY 11TH SEPTEMBER: TWO-DAY SEMINAR AT THE OPEN UNIVERSITY, MILTON KEYNES**

Over these two days, we heard presentations from UK self-advocates, family carers and academic researchers.

We also heard presentations from Japan about parent advocacy, and Japanese social policy.

The presentations had three main themes:

- Family and self-advocacy for people with learning disabilities, including 'working together'
- Doing inclusive research
- Community work to support belonging

The Omori family presented some of the activities of the i-LDK Super-College.

Hiromi Tanaka talked about participation in policy-making.

We talked about the idea of 'belonging' and what it means to us.

We displayed the 'Embolden' older carers exhibition.

Afterwards everyone enjoyed dinner together at the MK Hotel.



# MORE INFORMATION ABOUT THE JAPAN EXCHANGE

The Japan exchange was in November 2019. Activities were in Osaka, Hyogo, Nara.



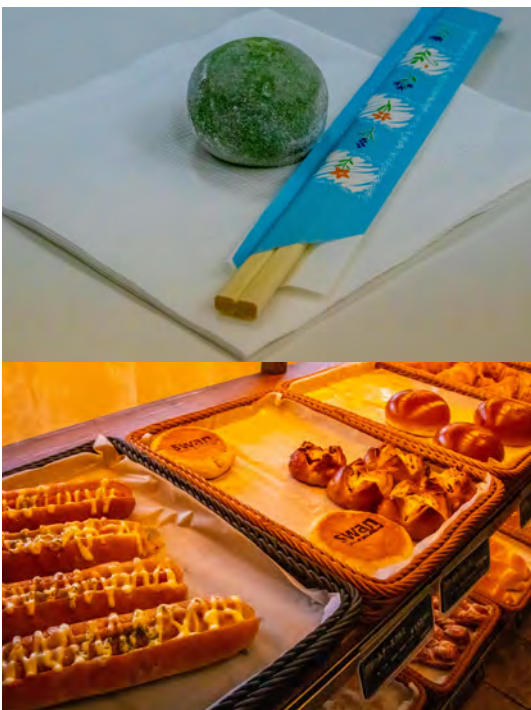
## FRIDAY 1ST NOVEMBER

We visited the SAKURA Work Centre and Group Home in Osaka. The service also provides respite care and runs a bakery and cafe called 'Swan' where we had a delicious lunch. Swan is a franchise across Japan. All the bakeries are staffed by people with learning disabilities.

In the afternoon we travelled to Kobe University for a presentation by Professor Eiji Tsuda.

Eiji talked about the history of self-advocacy in Japan. We talked about why self-advocacy had not developed much in Japan. We wondered if this could change in the future.

In the evening, we attended the 'Night Arch' event for people with learning disabilities and their carers organized by Eiji Tsuda at the University. People come to do music, dance and art activities.



## SATURDAY 2ND NOVEMBER

We spent the day at a seminar at the Good Job! Centre Kashiba in Nara.

People with learning disabilities, staff and family carers talked about their lives in Japan.

Ian Davies told everyone his life story.

Jan Sunman talked about the work of Oxfordshire Family Support Network.

Shun Omori did an Okonomiyaki performance over lunch.

Marin Fujino talked about the situation for people with learning disabilities in Japan.



Risa Matsumoto talked about sibling advocates in Japan.

We visited the Good Job! café and shop. We learned that people with learning disabilities involved in Good Job! design and make beautiful products that are sold in the shop – toys, ceramics, clothes, and pieces of art. The building itself was amazing and has won architectural awards. It was very inspiring.

We ended the day with a wonderful meal in Namba watching the chefs at work.



## **SUNDAY 3RD NOVEMBER**

A day of sight-seeing in Nara.

We visited the famous 8th century Todai-ji-Temple, and were guided round by a senior Buddhist monk.

At the temple we saw an exhibition of artwork by disabled children. Our guide explained how the Temple had always promoted inclusion for all.

We had a traditional Japanese lunch in Nara.





**NARA**



## MONDAY 4TH NOVEMBER

We spent the day at a seminar at Osaka University co-chaired by Shun Omori and Chie Kasahara. The Japan team was inspired by seeing Ian chairing seminars in the UK, and Shun was happy take on the role for the first time.

The presentations were mainly about inclusive research.

- Hiromi Moriguchi and Masashige Nakanishi told us about their work together
- Liz Ellis talked about her PhD research on family and community relationships
- Jan Walmsley and Liz Tilley talked about inclusive research in the UK
- Naho Honma encouraged us to think about how we can make connections with researchers beyond the field of learning disability
- Sara Ryan talked about belonging.

We learned that the word 'disability' in Japanese is closely linked to ideas about harm and barriers.

We ended the day with a meal in Namba.



## TUESDAY 5TH NOVEMBER

On the final day the team split into two groups.

Liz Tilley, Jan Walmsley and Ian visited Tenri University.

Ian presented his life story to social work students. Ian's life story helped the students to think about what 'belonging' might mean in the Japanese context.

Liz, Jan, Ian, Hiromi Moriguchi, Shun and Azusa met the Vice-President of Tenri University and his colleagues. We talked about our project, and what we were learning. We talked about what our network should do next.

Liz Ellis, Jan Sunman, Sara and Marin visited a rural day centre, which Marin's brother attends. There were some good things about the day service:

- some people with learning disabilities were doing jobs
- there were people making bread and cookies
- people were growing vegetables
- some people were weaving fabric
- the centre offered short breaks for family carers' respite.

But we also noticed that people who had severe learning disabilities did not have enough interesting things to do. As they have a place to go every day and connect with their supporters, they seem to be safe. However, it doesn't necessarily mean they are included in the community. Many work centres in Japan have same issue.

We ended the exchange visiting Tanpopo-no-ye, a not-for-profit organization that works with people with learning disabilities and their carers. Tanpopo-no-ye uses art to improve people's lives.

We had coffee and cake in the café, and then visited the art studios.

This was an exciting and uplifting experience. We were able to see how and where people create beautiful art and design.

We agreed that the UK needed more places like Tanpopo-no-ye.





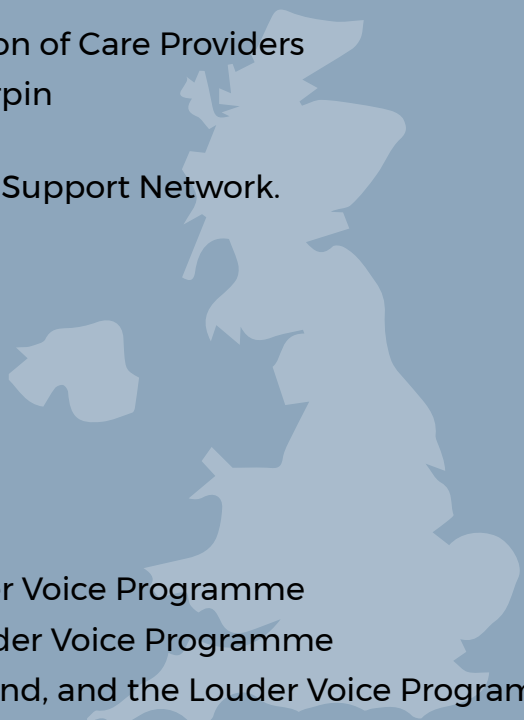
# TANPOPO-NO-YE



# LIST OF PEOPLE AND ORGANISATIONS WHO TOOK PART

## IN THE UK

Eddy McDowall, Oxfordshire Association of Care Providers  
Chris Ingram, Rachel Knapp, Daniel Orpin  
and Grace Kerrigan from Style Acre  
Kathy Liddell from Oxfordshire Family Support Network.  
Yellow Submarine, Oxford  
Yoko Myers  
Noelle McCormack  
Melanie Nind  
Karrie Marshall  
My Life My Choice  
Northamptonshire People First  
Liz Wilson, Dimensions, and the Louder Voice Programme  
Wendy Burt, Dimensions, and the Louder Voice Programme  
Gary Bourlet, Learning Disability England, and the Louder Voice Programme  
Melisanda Berkowitz  
Mio Kanie



## IN JAPAN

SAKURA Work Centre and Group Home  
Eiji Tsuda, Kobe University  
Good Job! Centre, Kashiba  
Tanpopo-no-ye  
Naho Honma, Osaka University  
Risa Matsumoto, Kanazawa University  
Masashige Nakanishi  
Masako Suzuki, Panda-J  
Keiko Ota  
Miki Matsuda  
Hirokazu Fukaya and students of his class, Tenri University  
JP-Challenged Co. Ltd  
Shimura Gakuen Special School  
The Itabashi Safety Network  
Group home run by Tokyo YWCA  
Rev. Kojo Morimoto, Administrative Manager of Todai-ji Temple



And many thanks to our interpreters Dolly Thompson and Moe Ichimura