UNIVERSITY OF BIRMINGHAM

SCHOOL OF PSYCHOLOGY

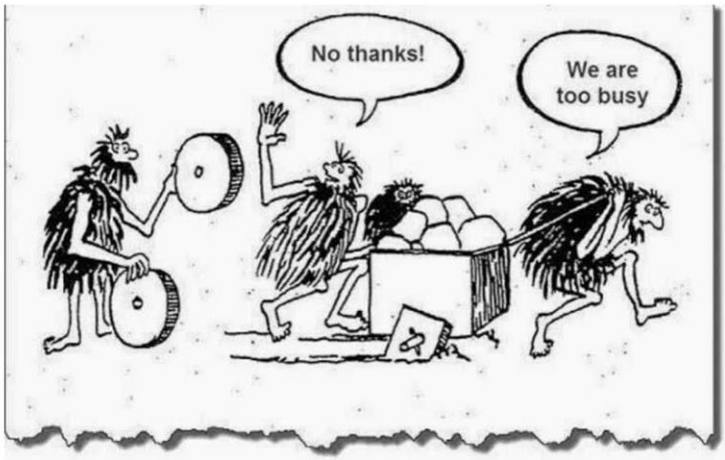
How can we reduce difficulties with changes to routines and expectations experienced by people with neurodevelopmental disorders?

Dr Kate Woodcock

k.a.woodcock@bham.ac.uk

I am Kate Woodcock, and I am going to talk to you today about some of the work that my research team has been doing, and will be doing in the near future, specifically focusing on the difficulties with changes to routines and expectations that individuals with neurodevelopmental disorders can experience.

Resistance to change

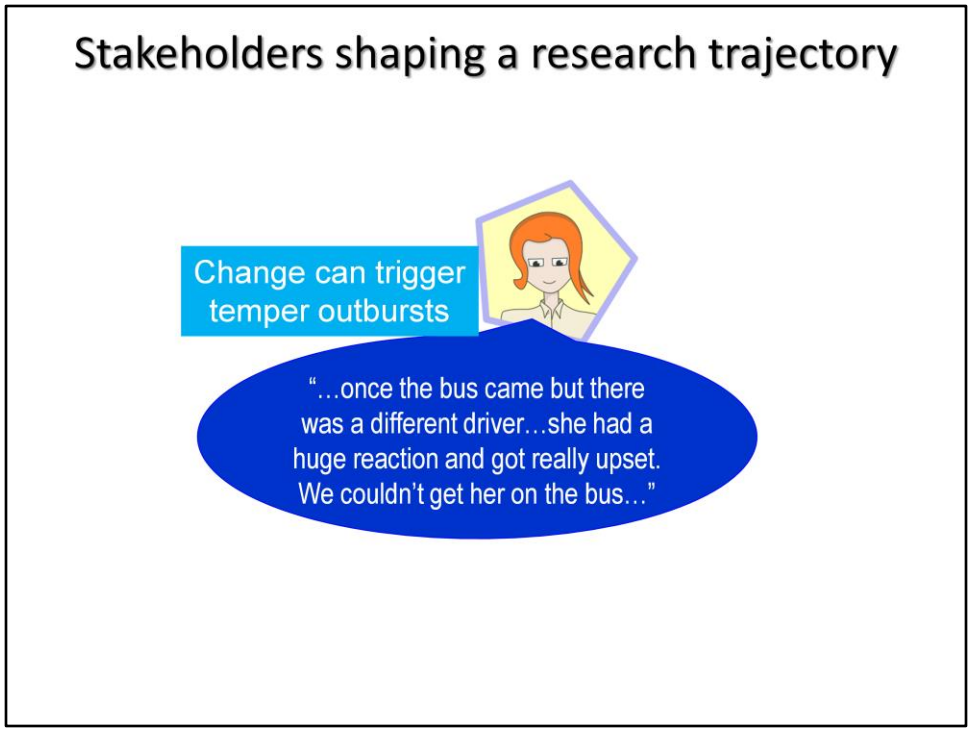


Autism spectrum disorder	Prader-Willi syndrome	Fragile X syndrome

So we know that resistance to change is a common problem in individuals with several different neurodevelopmental disorders. I have listed some of those on this slide but this is not an exhaustive list, I have just picked out these disorders because several of the projects I will talk to you have involved populations with these disorders.

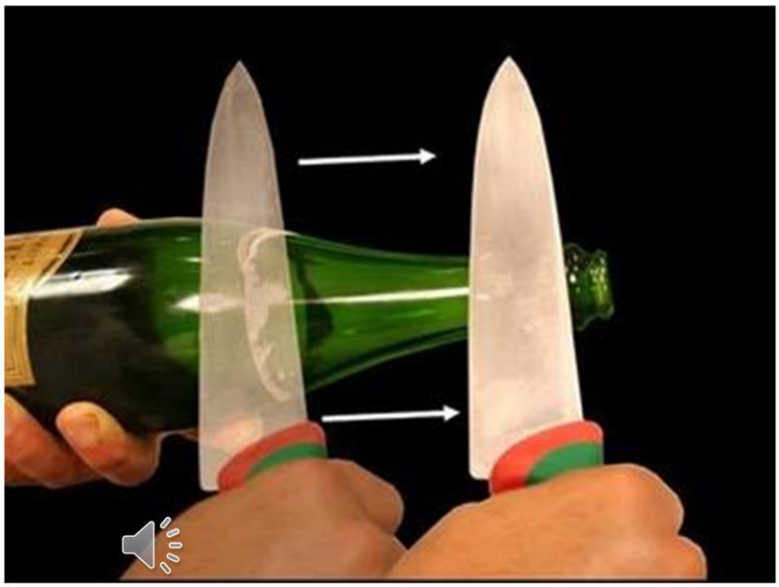
One of the largest challenges around resistance to change is the challenging behaviour that can follow changes to routines or expectations.
So that we're all on the same page when I talk about this, I want to show you a video where an actress has worked with us to illustrate such behaviour (the sound isn't great but you will get the idea).

So the work that I am going to talk to you about today aims to better understand the resistance to change shown by individuals with neurodevelopmental disorders, and to develop intervention strategies aiming to reduce such resistance to change.



I think at an event like this, it is important to mention that what set me along this research trajectory was input from stakeholders.
12 years ago near to when I first set out in research, I was interviewing the parents of individuals with Prader-Willi syndrome about the repetitive behaviours that their children showed. One of the most striking things from these interviews was the importance of routine for this population, and the behavioural problems – often temper outbursts – that were frequently triggered by changes. This shifted my focus very early on and taught me a very important lesson. If we are aiming to conduct research for the benefit of certain sectors of society, then in my view it is absolutely essential that we work with stakeholders throughout the research process.

So, as I said, one important aspect of the resistance to change research, has been aiming to develop effective helping strategies that will reduce the disability linked to resistance to change that the families of individuals with neurodevelopmental disorders can experience.



One important strategy that we have focused on is based on a very simple learning technique
The strategy aims to make changes more predictable by preceding them with a very obvious, distinctive signal.

Even though its simple, I think it helps at this stage to actually experience how it works.

So, in a few seconds I'm going to play some very loud and nasty sounds so if you have sensitive hearing, you might want to cover your ears.


NOISE!

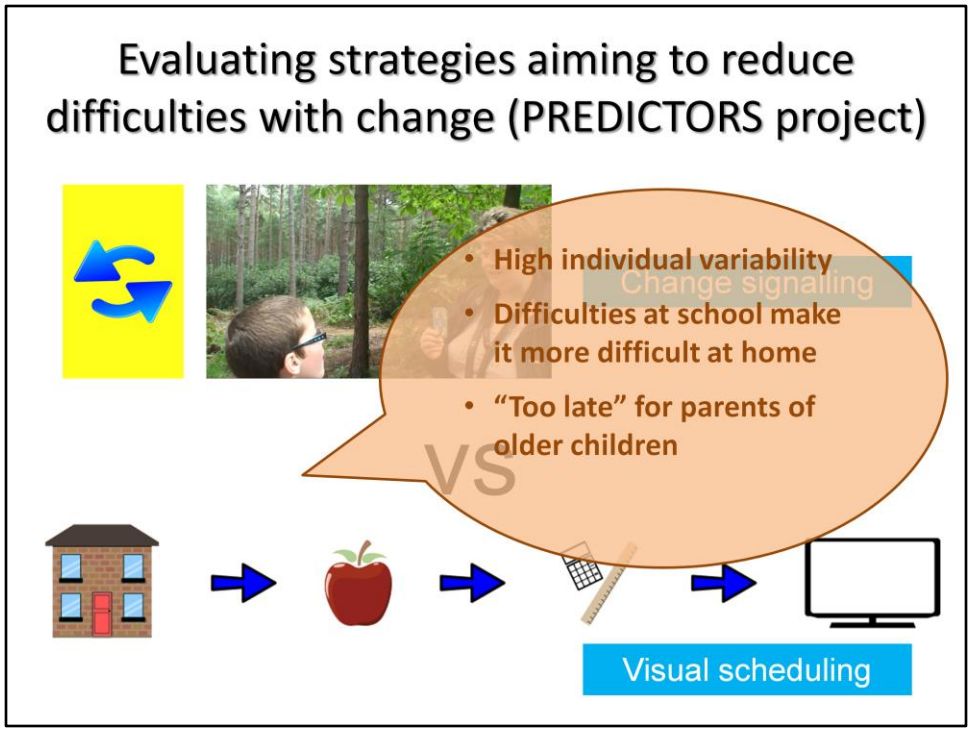

NOISE!


NOISE!

How many of you were expecting me to play the sound again and had already prepared yourself for that?
Probably quite a few of you.

Many of you will have noticed that each of the first three times I showed you the yellow noise warning sign, I went on to play the noise. So you were able to learn an association between seeing the yellow noise sign, and the nasty noise being imminent. That should have allowed you to prepare yourself for the noise and that's also why when I didn't play the noise the final time you may have been a little surprised.

Hopefully you should have also noticed that the last time I played the noise, it wasn't quite as bad as the first time because you were expecting it to happen.



Our signalling strategy that I mentioned uses a similar approach to the noise sign before the knife on the bottle noise.

We ask parents and caregivers to show a signal card that is bright and distinctive and say a standard verbal phrase "something is going to change", whenever they learn that a change in an individual's routine or in what they are expecting is going to happen occurs.

We tested this strategy with a small group of people with PWS and showed that it seemed to be capable of reducing upset and temper outbursts linked to particular changes – in other words, if the same routine or plan was changed either after that change being signalled or when the change was not signalled, individuals with PWS got less upset and showed less temper behaviours when the change was signalled.

In a more recent study, we have worked collaboratively with families and professionals to produce a set of web-based training tools that caregivers can engage with to learn how to use the signalling strategy, and how to use another strategy that we developed as a point of comparison, using visual schedules to plan to avoid problematic changes.

The idea behind both strategies was that they are based on tried and tested behavioural principles, which have a strong evidence base, but that they could be

delivered in a relatively resource efficient way.

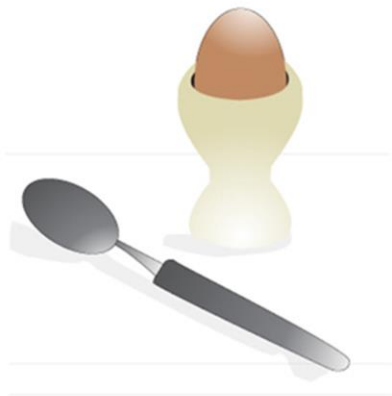
However, the results of the randomised trial that we ran with families affected by a range of neurodevelopmental disorders, including ASD, PWS, FXS and ID, highlighted a number of challenges with these approaches.
There was a lot of individual variability, one strategy might work best for one individual, and the other strategy better for another – but this might also vary across time.
For some families, difficulties for the children at school affected how able parents felt to engage with the strategies at home.
One of the avenues we would like to pursue in future linked to these issues, is whether we may usefully develop the training resources into a package focusing on the needs of mainstream school teachers, who manage a continuum of children's needs in terms of ability to deal with change. This may help to address limited availability of training on neurodevelopmental disorders and related issues for mainstream classroom teachers, and contribute to ensuring such classrooms can meet the needs of all students.

Finally, several parents of older children in the sample, felt like these strategies came too late, because they had already worked out the principles for themselves.
This alludes to the importance of early intervention, which I will come back to in a minute.

Why do some individuals with neurodevelopmental disorders find change so difficult?

So far, the strategies I have mentioned are based on tried and tested behavioural theory – we don't really need to think about what's going on in the brain at a cognitive level to understand why they work.
But by understanding more about the cognitive processes that might underpin resistance to change, we can open the gates to other kinds of intervention strategies.

Task switching (cognitive flexibility)



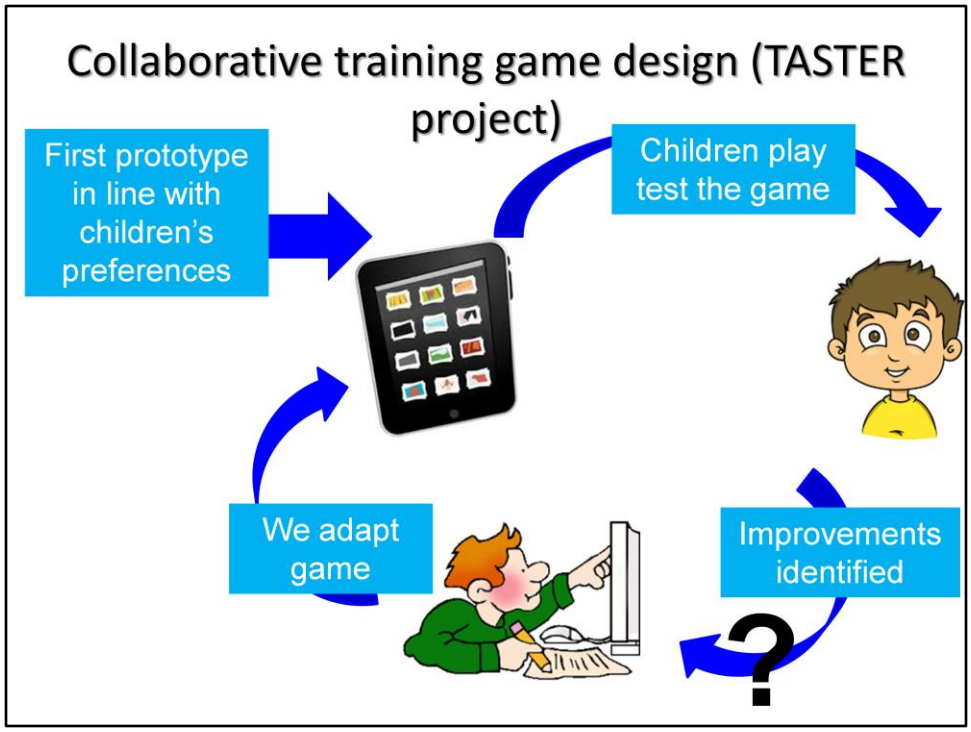
Task switching, which is ultimately cognitive flexibility, seems to be very important for dealing with change.

Task switching is what we would rely on for example, if we have to *switch* between using a teaspoon to crack open a boiled egg and so thinking about the teaspoon as a heavy object capable of cracking an egg shell – and using a teaspoon to eat an egg and so thinking about the teaspoon as a concave object suitable for scooping out a runny yoke.

Switching demands trigger temper outburst-like behaviours

There's several lines of evidence that suggest an association between task switching and resistance to change.
I just want to show you a quick clip from some of our research from quite a while ago.
Here you can see Becky, who has Prader-Willi syndrome doing a computer task that puts different levels of demand on task switching. You will see that when demands are made on switching, Becky starts arguing – she also showed other behaviours that were reliably shown during her temper outbursts and other challenging behaviour triggered by changes.

If placing demands on task switching is capable of precipitating challenging behaviour linked to resistance to change, then in theory if we can improve task switching skill, then we should be able to reduce resistance to change and associated challenging behaviour.



In our TASTER project, which is currently ongoing, we are developing a computer game specifically for the purpose of training task switching in children with neurodevelopmental disorders.
It has been primarily focused on PWS because it is the Foundation for Prader-Willi Research who have supported the work. But we have also been working with some individuals affected by autism spectrum disorder.

Importantly, the way we are developing the game relies critically on the involvement of stakeholders. We use what is called a user-centred design process where we design a first prototype of the game in line with the needs and preferences of the individuals who are going to use it. And then we keep improving the game in an iterative cycle, also in collaboration with individuals who will use the game.

Initial evaluation of our prototype

Child ID	Change in performance compared to just practising switching tests	
	Period 1	Period 2
1	**TASTER: ↑ (~3hrs)**	PLACEBO: ↓
2	PLACEBO: ↓	**TASTER: ↑ (~1hr)**
3	PLACEBO: ↔	TASTER not completed
4	PLACEBO: ↓	TASTER not completed
5	PLACEBO: ↓	TASTER not completed

After the first few cycles of development, we tested the prototype game to see if it could bring about a beneficial effect on task switching.
This is a summary of the results. Ultimately we did show that the game was capable of improving task switching over and above the benefits in switching that one would see simply from practicing the tests used to assess switching ability. This was a critical step in showing that we were on the right track in our game development.

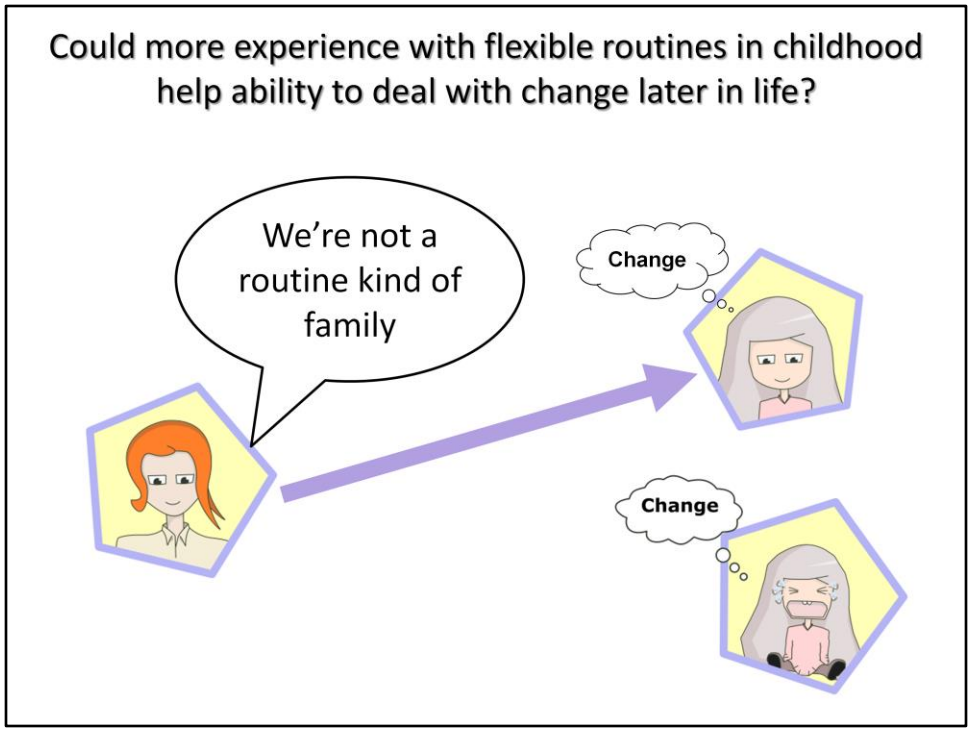
But it was just a small, very limited period trial.

Now we are developing the game further. Our priorities are to give it much more scope to motivate players to engage for relatively long periods of time. We are aiming for 30 minutes of engagement per day over a 5 week period.

Our developments will be finished over the next few months and we will be evaluating the training – and any effects it may have on resistance to change behaviour, just before the summer.

Moving towards early intervention for resistance to change

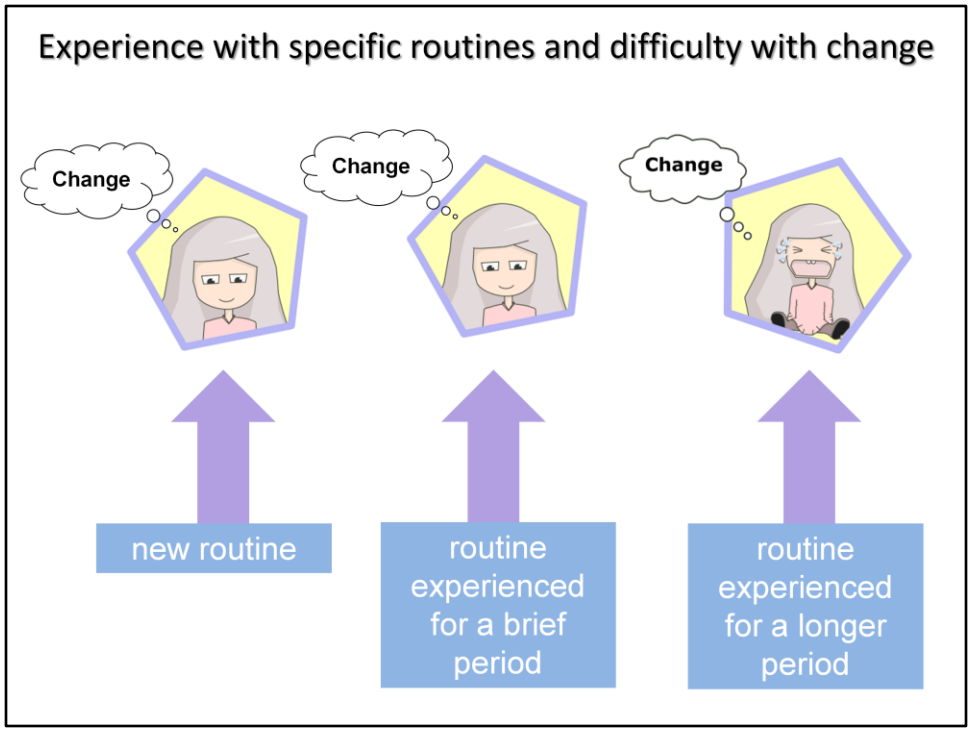
I mentioned before how parents in our PREDICTORS study highlighted the importance of early intervention approaches for resistance to change.
And this is the avenue that we want to take with another research project that has just begun.



In work from a while ago interviewing families, we found anecdotally that families whose children showed relatively little difficulty with change, also seemed to be those families who have never really implemented strict routines.

This raises a question about whether being exposed to some flexibility in routines from an early age may actually be beneficial for the development of switching and one's ability to deal with change.

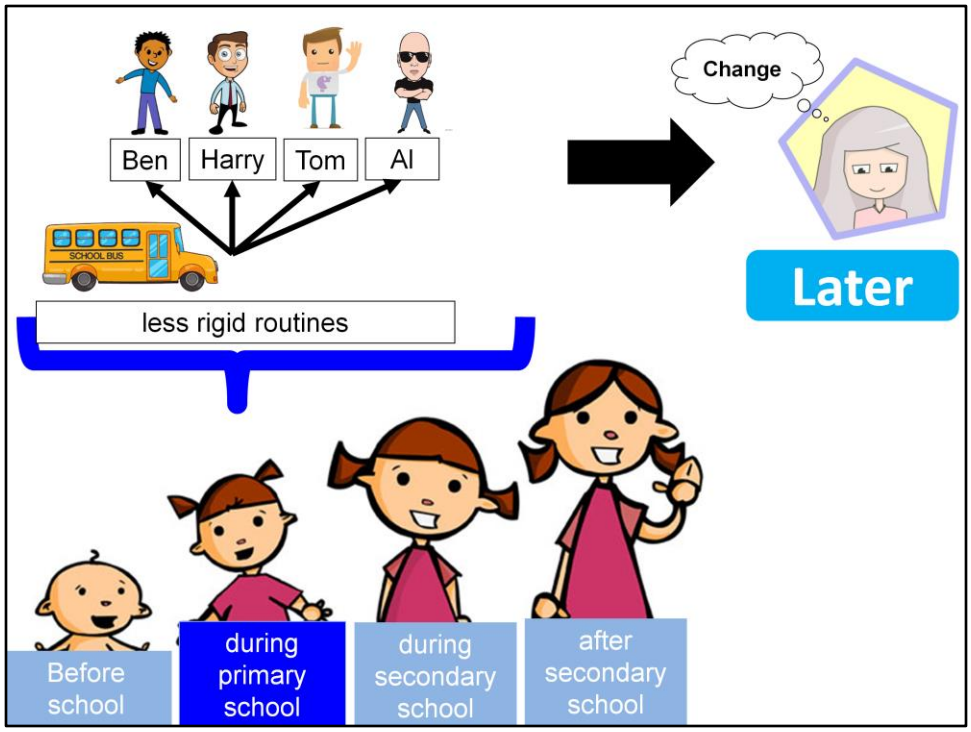
Indeed, there is evidence that typical pre-school children who are exposed to more flexibility in routines, do better at task switching tests; and that computer learning models exposed to more variable learning sets (so ultimately more flexibility), learn to switch more efficiently.



In an observational study in carefully controlled game based settings similar to the kind I showed you a clip of Becky before, we gave individuals with PWS routines that they had experienced for different periods of time – from five minutes, up to just under an hour and a half.

We found that individuals experienced higher physiological arousal and showed more temper behaviours when we went on to make changes to the routines they had experience for a longer period, compared to those they had experienced for a shorter period.

So this adds to the question we raised before – could more flexibility in routines at an early age be beneficial?



We also interviewed parents of individuals with PWS asking them to think back about routines and difficulty dealing with change at different stages in the individuals' lives.

We found that individuals who experienced less rigid routines during their primary school years, also showed less difficulty with change later in their lives.

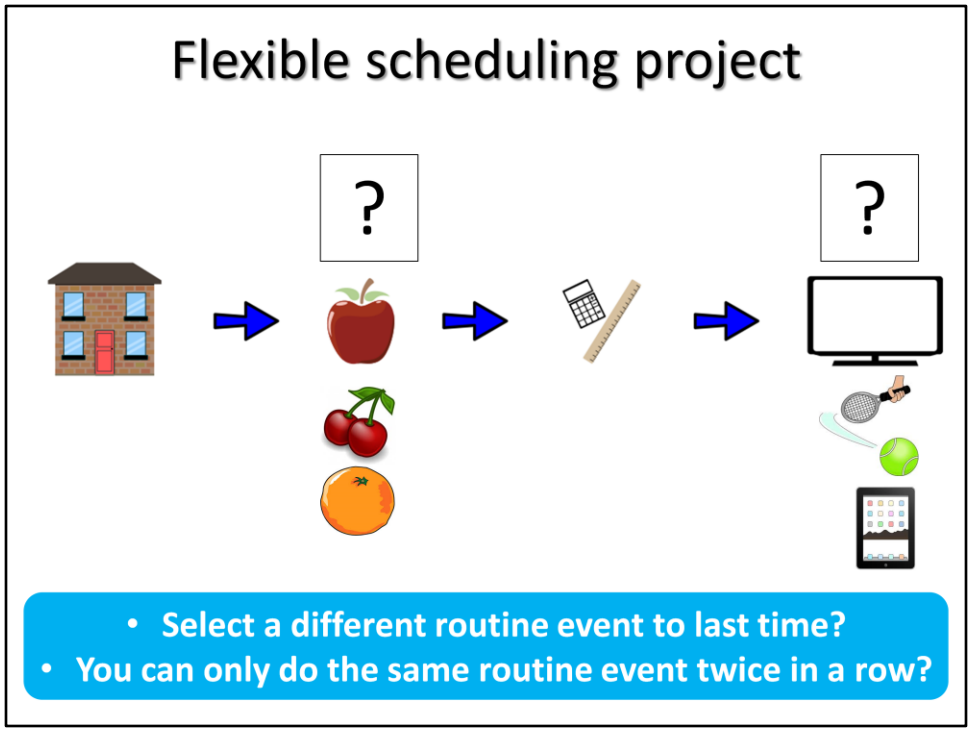
Obviously with an interview study like this, there are many limitations because parents are reporting after the fact about children's behaviour and may not remember accurately. But these findings do fit in with the anecdotal reports I mentioned before.

Could systematically exposing children to *enough* flexibility in routines from an early age, prevent the development of resistance to change?

Together, these findings suggest that exposure to *the right* level of flexibility in routines from an early age, may facilitate the development of task switching, and be beneficial for subsequent ability to deal appropriately with change.

But we also know that children with neurodevelopmental disorders can begin to show resistance to change from quite early in life, and often strong structure and routine is recommended as a part of best practice for working with children with neurodevelopmental disorders. So this hypothesis raises an important dilemma.

What is *enough* flexibility?
What is the *right* balance between structure and flexibility?



We have now just started our *flexible scheduling* project.

In this project, we are aiming to develop an intervention that will allow us to strike that *right balance* between structure and flexibility.
What we have in mind at the moment is a visual scheduling approach where option or choice points are systematically included in the schedule.
The key objective will be encouraging children to work with the schedule in such a way that they earn that engaging in routines differently to how they have engaged with them before (so in a flexible way), is rewarding.

After developing the intervention, we will also be testing how feasible and acceptable it is for families.

Our first step will be to work closely with a group of professionals who have experience in working with children who show resistance to change and/or visual schedules. We are recruiting that group of professionals at the moment.

Once we have developed a starting point, we will work closely with the parents and teachers of children with autism spectrum disorder, Prader-Willi syndrome and fragile X syndrome, to collaborate on refining and improving the intervention (in a similar way to the one I explained with the game development).

Siobhan Blackwell is coordinating this and she is here today, so if you are interested in finding out more, please talk to Siobhan or I.

Once we have developed an intervention that is both feasible and acceptable, we will be in a position to take it forward into a trial to evaluate whether it works.

Thank you!

And thank you to….

- Sarah (the actress)
- The wonderful families who participate in our research
- All of the hard working members of my research team
- PWSA-UK, PWSA-Ireland, Fragile X Society, ASD-UK, Autism NI, and other organisations who supported recruitment
- Our supporting funders
- Chris Oliver and CNDD

- **NOW recruiting for the flexible scheduling project – please get in touch! S.Blackwell@bham.ac.uk**

Ciaran Ball
Leah Bull
Cora Derry
Alice Donnelly
Áine Fitzpatrick
Maria Garcia Edo
Katherine Grady
Elaine Haig
Jason Hassard
Jordana McBurney
Clare McGeady
Lynne McGowan
Morgan McKenna
Roisin McKenna
Leon McMannus
Niamh O'Kane
Jennifer Norling
Jessica Pimentel Leon
Glenda Preston
Naimh Rainey
Joanna Reed
Nigel Robb
Kate Ryan
Marlene Trimble
Janis Wright

FONDATION Jérôme Lejeune 20 ANS DE DÉFI SCIENTIFIQUE ET ÉTHIQUE
MRC Medical Research Council
The Baily Thomas Charitable Fund
bt cf
FOUNDATION FOR PRADER-WILLI RESEARCH