**Edited Transcript**

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Day 1

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**CHILDREN**

**Session Chair: Sharon Fingland**

**Assoc Prof Lisa Stafford: Where are the children? Positioning children, young people with a disability and their families in the universal design agenda**

***Synopsis:*** *Much of the discourse around universal design assumes an adult perspective and consequently children are left out and become invisible in the designs. Lisa argues that we must include children, including those with a disability and their families if we are to truly be representative in our policies and practices in universal design, and not consider them as an afterthought.*

I'll be stepping back a bit and looking much more broadly than just play environment. So what I'm really interested in and have been studying is children's participation in everyday spaces, so not just the play spaces but our neighbourhoods, our schools, and how can universal design, the agenda and discourse, get behind and actually better consider young people and children at the present time ‑ I think we can all agree that their presence is quite limited.

So I want to start with this quote because it drives my passion, it drives my work: “Each girl and boy is born free and equal in dignity and rights; therefore, all forms of discrimination affecting children must end. We will take all measures to ensure the full and equal enjoyment of all human rights and fundamental freedoms, including equal access to health, education and recreational services, by children with disabilities to ensure the recognition of their dignity, to promote their self‑reliance, and to facilitate their active participation in the community."

Unfortunately, as we know from the UNICEF reports, children with disabilities are one of the most marginalised people in the world. I wanted to highlight some of the areas where the current points of intervention are for us, where there are barriers but where opportunities lie for all of us as a group, particularly in the discourse of children itself, children's research, and how we understand participation. I know Gerald mentioned the ICF today, but the ICF actually has a specific specification for children and youth, but again it's an add‑on.

I want to really talk about recognition. Recognition is one of the most significant parts of actually progressing inclusion and that's a really key point, particularly in planning. Planning I will focus on a bit. Planning, policy and legislation ‑ they're key instruments to progressing.

And I'll quickly look at the implications in different urban spaces, so just broadly about what is happening. So discourse ‑ this is really brief, this is a quick summary, but in general children with disabilities aren't well researched within the broader children's geography urban studies research in terms of their experience of urban spaces, and what research we do have around children with disabilities is we generally focus on function and impairment and it's services perpetuating use, without really focusing on their progression or participation or inclusion. We know they're more susceptible to discrimination, that's clear, their voices are continually ignored, and even within the children's environment. Choice of mobility for many is rhetorical, and there is a lack of opportunities in general for children with disabilities.

This diagram just illustrates for participation what we're talking about is not just the participation in activities, but a participation of voice, a voice about choice and agency. And my own study expanded that further. So for children with disabilities and particularly older children when we're getting into the 9 to 12, where social identity is so important, that genuine participation means that you have to have agency, you have to have affordance. Affordance and resources, not just resources in terms of supports and services, but knowledge, that they're actually given access to knowledge, to make choices.

A sense of place, that they have a value and purpose for what they're doing. And ultimately enjoyment, fun, it has to have value. This is P4's quote about one of his experiences, “because it's fun there, they do look after you and make us feel like normal because they let us go on anything”.

Unfortunately, most participants are actually seen as non‑participants. They experience non‑genuine participation, this is not just in the playground, this is in schools in the neighbourhoods. The other thing is they're often bored, boring was a common experience because they're sidelined.

What we actually find is that participation is actually a journey becoming involved, and this diagram represents the model I mapped about how children and their families go about participating in everyday spaces and it actually starts before you leave home. It's the planning and I know Sally talked about planning. It's planning that had to think, most of the environments they know don't accept who they are and how they move and interact in space.

It even occurs at the onset, so actually getting out the front door, children's mobility needs are critically important and then getting into the vehicle. If you don't have a family vehicle that accommodates your way of moving in space, which is especially children who are using manual wheelchairs or electric wheelchairs. The family didn't have access to vehicles; they were very bounded in terms of their experiences.

Even then when you get to somewhere, can you get out, can you park? How far is it to walk to somewhere. Then you actually get inside it. So this whole journey, it's about that experience. Any time on that journey there are points and tensions mapped. They have to at the beginning pick and choose where they go, find a way or avoid, as we've heard. Along the process you can discontinue where if you can't get a park at a shopping centre, you actually may have to return home. There are a whole lot of aspects that affect not just a child's inclusion and participation but the family unit.

Recognition is key. We know that recognition as a theory, we know if people are afforded generally opportunities, it's because people are valued. They're actually considered about their abilities and worth and value. We know this in terms of disability theory. We know that the recognition of one's self by others is critical in terms of being afforded choice, opportunities. Those are key starting points.

Even the new sociology of childhood children in general about how we conceive them, and recognition is one of the most significant points if we want to make change and seeing them as active participants.

Unfortunately, mal-recognition and non‑genuine recognition are generally experiences. Mal-recognition is when one is not even considered, and the non‑genuine is when we have partial or token recognition, it's fake, it's so well known. It's even considered as one of the worst forms of recognition.

But it's funny, Fuller uses the whole analogy that this is something that doesn't need to be here, this is completely preventable and avoidable.

This is just an illustration of a young girl who was talking about school and school banning her from any of the social spaces in school. My question was and what did you think the main problem was? “Because they were worried about my safety which I think was very lame. You know what schools are like, they're overzealous, they think they're responsible in she rolled down the bloody hill or something. I'd just like to say let the little girl have a chance. If they go and get hurt, then say no. But let them have a chance. I would just like to tell them that disabled people have rights and I think they get overlooked. There is a real recognition children are aware not only they're not given opportunities, but the reasons why. I think we don't give children enough credit”.

So what we're finding, in terms of social‑spatial barriers, particularly where universal design can really help progress this agenda is that how we homogenise children and spatial needs in general. Yes, there are similarities but there are some clear differences. The other thing that we find within even our access standards is that children are rarely recognised, our legislation, standards, our planning schemes, our strategies.

The body tensions of homogenisation, for a classic example, this is a common image we see, the adult body. When I was talking to young people, what was really clear was that even products that are designed for accessibility is perceived and actually experienced by them as actually not ‑ it doesn't fit them. We talk about environmental fit or product fit here, and P2 says "yeah, it's very bad. All it is, is a big chair with big fat wheels and arm rest. It's so big my arms can't even reach the arm rests, so it's ridiculous. I asked him why and he said "I think they designed it for adults." "Do you find that often" "Yes".

The other gaps and problems in recognition are disability standards for access which make no reference to children and we certainly don't reference the 1428.3.

Disability standards for transport, we exclude the school bus, the designated school bus doesn't actually even come into play and there is no change in the future. I've had numerous discussions. That's not just the to and from school, but it's also to excursions, to the swimming pool.

And there is very limited universal design guidelines to help inform the planning and design of schools. Yes, buildings, but children don't just go to buildings. It's about how they experience, use and interact in that space. There are all activity nodes in this one major specialty. Open spaces and facilities ‑ we've heard about play environments, but for older children and young people, they need adjusting and changing. So we need to think about them. A lot of young people report there's really nothing for them. Neighbourhoods ‑ I'm doing a presentation tomorrow about neighbourhoods, but this is a place where so much more work is needed. We may have a great accessible house, but if you can't get out and socialise and even move past that front door and go over and say hi to your neighbours, then the neighbourhood is one of the first points where children actually become independent in terms of their mobility, in terms of being able to even have free leash and play. So they're all key areas in everyday life and participation that we can really focus on.

Planning plays a pivotal role here. I know there is no systematic legislation that binds. Every council has their own planning scheme. But it's an opportunity. One of the biggest things too is that we rarely focus on spatial needs beyond the playground and that's well documented, not just for children with disabilities, but for children in general.

Access and equity plans are fantastic and they've made huge changes at local council level, but we can think about participation and progress them a bit further, and particularly around looking at children's needs as well in those, not just from an adult's perspective.

And open play strategies ‑ whilst we've had excellent illustrations about the all‑abilities playgrounds, we also need to look more closely to home and particularly for families that don't have the ability to travel far. So how can we be more smart about our neighbourhood design and look at activity nodes within the neighbourhoods that aren't necessarily spaces, but a whole range of spaces in which people can safely explore and have free play experiences.

So barriers unfolding. In terms of when we started mapping all their experiences, Liberty Swing ‑ I think Kelly mentioned this swing. The biggest thing is even when we provide access, there's a disconnection to how people are going to use and experience that, and here is a classic example. The illustration here is about where the Liberty is facing the buildings, so if you position there, you're experiencing the road and buildings, whereas behind is the beautiful background. The other thing is it's due west and in Queensland it's really hot, so not only is it going to fry you, there is no shade, but again it's this disconnection how people will experience a new space.

School ‑ as I mentioned before, there is such a disconnection. We might be able to provide access to a building, but children are moving between buildings, especially once we get into high school, we're moving between buildings quite often. The other thing is there are so many social spaces that are in between that are going on and for this young boy he always says he has to go the long way around. The red path is that kid's journey, where all his friends go the blue path. So it continually reinforces difference and separation and just simple things about how we could really think and plan differently about our buildings.

The other thing is token provisions. I don't know how we go about this, but schools are very complex and we know that schooling in general around education for children with disabilities is pretty bad. But the classic example is when we provide access and I think someone talked about it before, we talked about the tick the box, this is a classic example that happens within schools. But we see that in parks and also car parks and every environment where we use these minimum standards. But the whole idea about not actually understanding and listening to children's needs was really clear in this quote. I'll read it out for anyone who needs it. I asked "Now we talked about the benches that you wanted, like have you got them yet?" P3 says "Yes, but not where I play. It's like somewhere like over there." And I said "So they didn't talk to you about where to put them?" "Yes, but there was a concrete slab already there so they put it there". Even when we do ask, we're not even listening.

As I mentioned, excluding the school buses. It's so clear. People go why do we have to provide school buses? People don't understand that the school buses are social, it's not just about transportation, it's about this whole journey where you talk, communicate, you start working out who you are. They're not even getting the opportunity because we've already said oh, well, they're not worth investment in. This is clearly why they go in taxis while the other kids go on the bus. I'll read M2 "…whereas here, you know, if your child is at school and they are in a chair there is no buses, the buses they hire to take him on the sports day of school excursions none of them are wheelchair accessible. So there has to be alternative arrangements made as in you have to take your private car". That's if you have a private car. Some of the families in my study didn't have access to those.

The other problem is at 12 years of age, who wants to hang out with their parents? Again we haven't really thought through the transport standards, we've written them off. It will be interesting to start doing a cost benefit analysis. I'd like to, but they didn't fund me. A cost benefit analysis, how much do taxis cost every day to school for every child of their 12 years of schooling in terms of actually making buses accessible?

Bounded to your driveway in your neighbourhood. Not many children were able to venture out. This particularly was not just because of cars, but most local streets don't actually have footpaths. There are very few designs and even in our new designs local streets don't get rated because of the assumption that people don't use them or the traffic volume. But the problem is we still have a speed of 50 kilometres. We all know that serious injury still occurs at 50 kilometres, not to mention we have spillover because of the intensification of our neighbourhoods car parking, there are not just one or two car parks in homes now, we have spillover into the roads.

The other thing is we've narrowed streets in our local streets, so what happens is effectively the roads are the footpath where the cars are still travelling down and we haven't looked at do we need to rectify the speed limit here. The UK have started looking at this around home zones and I think they've looked at 23 kilometres. We need to have debate. This is not just for children, this is for everyone. If we want to look at multi‑generational planning, it's a key area we need to focus on for older people as well as for children and young families.

No place to change, I know Sally mentioned this, but it's critical, not just in the play environment but for older children who can't weight bear, parents can no longer lift. If you have nowhere to go and change the child who requires that attention, then a lot of the times families will start simply avoiding places ‑ shopping centres we don't have, we have accessible toilets, but families shared experiences that they have to change on the bottom of a floor of a toilet. Is that acceptable? That's the implication. We don't think about as a child gets older the implications are more impactful for the family unit.

We've talked about the parks and playgrounds, and these are new parks in new developments. We're actually providing access to the swings now, but you can't get to them, you certainly can't really get on to them. Anyway. Again there's a real disconnection between providing access, and designing for participation.

Carparks and entry points, I think we've all experienced car parks, but children ‑ again, it's a really big maker and breaker in where families choose to go and where they go. These quotes here, when I asked the children where could I go to take a good photo, P2 says nowhere, P8, when we were talking about the disabled parking and for her she walks with crutches, for her the disabled parking is supposed to be close, it's over there and I can't, by the time I get there it's oh my God this is supposed to be disabled parking, by the time I get there I'm poofed.

P7 who uses picture communication symbols to communicate, he quite clearly symbolises parking quite well, stupid parking.

So the implications for children ‑ as I said, they're alone, they don't get to hang out with their friends, and they're bored. The implications importantly for families are that when your mobility and options are bounded, your opportunities and freedoms are impacted. And this map that we did of M4/P4's family is the mum summed up her experience, this is all we ever do, it's quite pathetic really, and M5, if it doesn't suit you don't get to go or someone doesn't get to go.

So the future focus ‑ I think there's a real opportunity to recognise children and young people with disabilities in the universal design agendas. I think something we haven't done well and I think we certainly have enough passion and drive here to actually ensure that they are better spoken about, and ways we can do that is much more effective engagement with children and young people. They are really good, articulate and clear about their needs. I would love to get children with physical disabilities on the school buses and I think collectively we can all be a part of that. And I think we can work together about more universal design policy and design for specific spaces, so as I mentioned like schools, because the problem is to plan a design, it's quite complex and we have standards and information all over the place. So bringing together some synergies and integrating this makes it a lot easier and it helps translate research into practice, because that's one of the biggest barriers, while everyone talks about, it's great to have the research but who has access to it and how can we implement it?

So just in summary, children and young people want ordinary, everyday lives, with genuine participation experiences like their peers and siblings. I think we all need to be part of the solution to actualise children's rights. So thank you.

SHARON FINGLAND: Thank you very much. Do we have any questions?

DELEGATE: I'm Noelle Hudson, I'll put on my other hat, I'm a child advocate. It struck me really clearly when you were talking about access for children to engage, we've legislated them to stay in areas we want them to be and actually children need creative space and it's quite often going where you're not supposed to go and being able to hang out with whoever you want to hang out with and maybe people your mum doesn't want you to hang out with, but by limiting those set areas in the playgrounds or in the school, we've got kids where we want them to be. Have you struck any sort of environments where kids have freedom to roam, freedom to have a quiet chat with their friends, especially as they get older and they don't want to be supervised? Have you seen that within your study?

LISA STAFFORD: I think more in practice. Sally and both Justine and Bec have shown some examples of how it has happened in play spaces quite well, when you're truly universal, participatory design examples. I think we have a long way to go in terms of young people being able to freely go out their front door and go down to hang out at the sports centre. As I said, most were bounded at their driveway, they didn't get the chance to go over and talk. I'm going into detail about neighbourhood design tomorrow. That's what we're talking about, there are tiny little examples out there, but nothing really concrete. I think we have a lot more work to do. We've talked about we need to do post‑occupancy evaluation, we need a lot more data and research ‑ themes we're talking about, not a lot of people want to invest. That's our biggest barrier too, getting the dollars, the research dollars to do the work too.

DELEGATE: Thank you. I just thought that was awesome and most of those things that you said rung very true, in particular schools. I think schools is one of those last bastions, where nothing is accessible, exams aren't accessible, buildings, the transport ‑ it goes on and on and it's really an area I think that needs substantial kind of investment.

I also wanted to make one point too and it was really nice that you articulated that kind of journey. In recreation and planning we use a thing like a trip cycle, which is exactly that, and it also has the return which is actually leaving whatever you're doing and the whole process of kind of reflection on the experience, because that's often something that particularly children with sensory issues have a great deal of difficulty with and it's one of those things that again in terms of design really needs to be thought about.

LISA STAFFORD: Absolutely. I couldn't agree more.

DELEGATE: I feel like I'm stealing the microphone today. I just wanted to say a couple of things again. When talking about school buses and accessible school buses, without a doubt, I agree 100% with you. Also trains, I live in the rural country, a lot of our excursions go to Melbourne. We've had children put in the baggage compartments and so on in trains. So things like that need to be advocated better. I do work in a council and we have an advisory committee, disability advisory committee, that feedback on all our projects. What I'll take back from today is we have no children we consult with. So thanks for that.

LISA STAFFORD: No, thank you. I didn't touch on regional. One of the big things is we talk about CBDs are getting fantastic, but where people are living, the outer suburbs and inner regions where most people with disabilities are living, especially in outer regional, according to data, there is so much work. Public transport, don't even get me started on that one. But in terms of being in the suburbs, yes, it's quite isolating. I didn't even touch on transport because families don't use it.

DELEGATE: I really want to comment a little bit on the neighbourhood, what you mentioned, because I have two little kids and we really get encouraged when I hear your research is working on that as well. Landscape architects talk about wildlife corridors, making sure I can go from habitat to habitat, but then I'm talking about human corridors, what are we doing as humans to navigate through our neighbourhoods. I grew up in a little town in Germany, play streets everywhere, I was out there doing crazy stuff, my parents never saw me, hurt myself every now and then. Nowadays I have to drive home, take my kids out, go in the house, when I want to go out there is no footpath, nothing, I have to put the dog, the kids, everything in the car, drive to the next park. It's encouraging to see what you're doing. I can't wait to see that Australia is changing there, that we can all play on the streets, so thank you.

LISA STAFFORD: It's funny, we talk about sustainability, but our neighbourhoods are so not. So focused on the car and not pedestrian focused at all. So thank you.

SHARON FINGLAND: I think that is time up now. Thank you so much, Lisa. (Applause).