

# LEGO® and Autism

By Shelly Timson and Rob Deakin



*Shelly Timson<sup>[1]</sup> sits down with Rob Deakin to talk with him about how he is using LEGO® play to help disadvantaged kids, especially kids with Autism Spectrum Disorders*

**Shelly:** Hi Rob. Could you please introduce yourself?

**Rob:** Sure. I'm Rob Deakin and I live in Melbourne Australia. I am 45 years old, married with two kids. I work in Cyber Security and I am an Adult Fan of LEGO.

**Shelly:** You are involved in quite a large number of LEGO related activities. Can you give people an idea of what LEGO activities you do<sup>[2]</sup>?

**Rob:** Ok. I have a business that prints on LEGO bricks. You may have seen the brick badges that people were at LEGO conferences. I print many of those and also print on minifigs. This has been a great way to meet people from LUGs all over the world and hear about their special projects and local events. Even better I print on bricks for many professional builders and get to find out about those special secret projects months before they are public.

**Shelly:** And the podcast?

**Rob:** That is the podcast I run called LAML Radio<sup>[3]</sup>. LAML stands for LEGO and MORE LEGO. It is another way I stay in touch with the community.

**Shelly:** It's not just a podcast. It is the longest running and most popular language podcast for Adult Fans of LEGO

**Rob:** Well maybe in English at least. I've even managed to have a few LCPs<sup>[4]</sup> on the show.

**Shelly:** We wanted to talk to you about the work you have been doing via ASD Aid. This looks like a fantastic program that AFOLs can get behind.

**Rob:** Well yes. I am hoping that eventually the AFOL community will support our program and we can get it happening globally. But we have a massive amount of work to do here in Australia first.

**Shelly:** Tell us about how you got involved with helping disadvantaged kids and what you are doing.

**Rob:** Well as you know I have had many opportunities to work with kids and LEGO over the decades. Through these opportunities I've seen firsthand the special benefits that LEGO

play provides. What we are doing is bringing those benefits to disadvantaged kids and especially kids in families impacted by Autism Spectrum Disorders.

**Shelly:** What do you mean by the benefits of LEGO play?

**Rob:** LEGO fans all over the world know about the direct benefits of LEGO play for kid's development. For example, in early learning and education circles you will find lots of information on how LEGO play is great for development of dexterity, counting and spatial skills just to name a few. However, what I am talking about is not just the basic benefits. I am interested in the magic that seems to happen when people gather to build something together. When kids are creating and building in a group it is a different social experience for those kids than playing sport or other group activities.

**Shelly:** So this is not just about getting the disadvantaged kids access to bricks?

**Rob:** We do that as well but that is not my focus. My mission is to create a place where these kids can connect through a common interest. So we can create opportunities to transform what is traditionally seen as a solo interest into something that can be shared with others. So after a lot of investigation I created a not-for-profit to provide access to LEGO play sessions aimed at families living with Autism Spectrum Disorders.

**Shelly:** Why specifically Autism Spectrum Disorders?

**Rob:** I started to notice this strange behaviour of some parents while watching their kids playing during LEGO sessions. Naturally many parents are quite impressed by their kids building skills or really like how kids interact when they play with LEGO bricks. However something entirely different was going on with a few parents. For example there were these emotional Mums trying to hold back tears or their bottom lip would be quivering. Initially I thought there was a problem, however I discovered that these were tears of joy or relief. I came to understand that these families were living with Asperger and other disorders and it was a very special moment to see their child playing alongside typically developing kids and being accepted. The parents explained to me that, while some families can find play opportunities for their special needs kids, many families miss out on the normal play or party invites that we all take for granted. As one Mum bluntly said to me, in the play ground, kids who act odd or quirky quickly get dropped off the normal round of play dates and invites.

<sup>[1]</sup> Shelly is a Female Adult Fan or LEGO, Girl Guide Leader and Mother of 2. She has direct experience of the challenges of living with ASD and is a volunteer leader at one of Rob's Clubs.

<sup>[2]</sup> Rob also runs LEGO workshops, parties and other events. He is one of the organisers of the Melbourne LUG (MUGs) and one of the people who pulls together Brickvention; Australia's premier LEGO Fan event which attracts well over 10,000 visitors.

<sup>[3]</sup> [www.lamlradio.com](http://www.lamlradio.com)

<sup>[4]</sup> LEGO Certified Professionals

**Shelly:** So you are trying to fill that gap with special sessions?

**Rob:** I don't call them special sessions. It is important not to stigmatise LEGO® play for these kids. From the kids point of view they are going to the Brick Club every month and meeting their club mates. They show what they have been building or they work on their current creations. It is the acceptance that is special. The parents know that we are providing a social meeting place and working subtly on the on challenges for kids with ASDs.

**Shelly:** ASD means Autism<sup>[5]</sup> Spectrum Disorders. People may have heard of Autism but we haven't really told people what that is and what these challenges are? So what is an Autism Spectrum Disorder?

**Rob:** The short answer is we do not know what it is. The cause is still unknown but researchers tell me that it is an alteration of brain development. Some say it is looking like having some genetic basis while others say that the evidence is not strong enough to conclude that. The top researchers in the world are still trying to work it out. I'm just a LEGO, guy not a medical expert so I would encourage people to read<sup>[6]</sup> more about it to get the full story about the complexity of the science. What I can tell you is what it means for the families I meet. Basically Autism Spectrum Disorders are a category of developmental disorders. It covers a very wide range of function levels across a spectrum of conditions, including Autism and Aspergers Syndrome. It includes people who have significant problems interacting socially and communicating and also have stereotypical behaviours like repetitive routines or deep obsessive interests. What is really important is to understand that there is a wide spectrum of behaviours. However in some people a combination occurs and that significantly impacts a person's capability. All these things come together and make it difficult for these kids to make and retain friends. ASD kids lack the kind of empathy and ability to maintain conversations that are important to sustain friendships. In particular role play and free use of imagination is struggle for many of these kids which can make playing with others difficult. They tend to be preoccupied with certain things and have very narrow interests and inflexibility to deal with change and want specific routines.

**Shelly:** These conditions are quite common aren't they? Do you think people know that?

**Rob:** It is quite staggering. The latest data on diagnostic rates is now 1 in 110 children and it is the most prevalent disability diagnosis in Australia. That rate is pretty much the same everywhere in the world from richest to poorest communities. What is not revealed in that figure is that it is 4 to 5 time more common in boys. I think because you can't tell an ASD kid from looking at them people is just not aware of the magnitude ASD in their communities. There are tens of millions of people especially in less developed countries that live in extremely difficult situations especially if myths and superstitions cause these people to be victimised or ostracized.

**Shelly:** So what help do these kids need?

**Rob:** The massive numbers of kids and the profound effect the disability has on both the individual and the family makes it hard almost everywhere in the world to get relevant, accessible and cost effective support. My very small part is focusing on using the innate interest many ASD children have in the LEGO system and providing a simple, extremely cost effective and practical way to provide impacted families with a place to help their kids develop their communication and social skills.

**Shelly:** Why do so many ASD children have an innate interest in LEGO building?

**Rob:** I don't know but they do. I discovered all these families with an interest in LEGO bordering my own obsession. I can now say that with a sense of humour having met and shared stories with many ASD families. Because you see for many ASD kids it actually is an obsession in the true sense of the word. So while AFOLs may joke about our affinity for the brick, for these kids it is a fixation at a very different level. But what I discovered was that LEGO was a much more productive and helpful focus than many other candidates in these children's lives.

**Shelly:** But why LEGO?

**Rob:** I don't know exactly but it is very important to understand is that ASD people are much more attracted to systems and objects. I suspect that LEGO play appeals because it has a structural logic in its design and provides a tactile or kinesthetic medium through which kids can work. An ASD kid may find other activities which involve lots of talking, abstraction, listening or observing difficult and prefer to undertake physical interaction with toys. So in LEGO play you "do" something with all these objects and see the results of your thinking materialise in front of you. There is no ambiguity in that result and there is an inherent system and logic in the building which is something ASD kids really desire.

**Shelly:** So you created these groups for fans of LEGO who also have an ASD?

**Rob:** Saying fans of LEGO may be true but you need to understand what I discovered about families impacted by ASDs. I found hundreds of families for which LEGO time was the major focus for their child; not just an interest. They didn't



<sup>[5]</sup> The word autism comes from a Greek word autós meaning self  
<sup>[6]</sup> [http://en.wikipedia.org/wiki/Autism\\_spectrum](http://en.wikipedia.org/wiki/Autism_spectrum)





know that all these other families in their community that were just like them. I was able to introduce them to other families and they started to realise they were not alone and could support each other. It was a lot like the early days of the AFOL community where adults started to find others with common interests in LEGO®. The difference here was that LEGO was a life line for these families not just a hobby. So we get the families together and the kids and their siblings play with LEGO bricks.

**Shelly:** So how do you see LEGO groups providing assistance?

**Rob:** Unfortunately, even in developed countries to get any Government assistance you need to have quite severe impacts. So many families of kids with milder symptoms of Autism and Aspergers in only one domain (such as inappropriate social behaviours) will not be able to get a diagnosis and will get no support. So at a very basic level just meeting other families in similar circumstances is something that provides support in its own right. But I am discovering every week other ways that these groups help. For example siblings often come to the groups and they get to meet other kids in similar situations. Can you imagine the strain on parents and the other kids over balancing attention inside the family? So at the club the big brother or little sister can meet somebody in exactly the same situation as they are in. That is really important conduit for communication for those kids (and they also get to play LEGO).

**Shelly:** What about the more basic benefits?

**Rob:** At its simplest, I bring a massive brick pile and provide that to the kids to play with. So at that a simple level a fatigued Mum just gets a break for a few hours in an environment where ASD kids are accepted. Now that would suit some families just fine but we are also trying to provide more than that. Many kids would happily solo play with all the LEGO bricks and sets we have for hours. With the expense of LEGO sets in Australia disadvantaged families don't have much and we are able to let them use our collection to provide a chance for the child to build more freely. The kids love to play with all the different elements and parts I bring.

**Shelly:** But you do much more than give parents a break at your sessions don't you?

**Rob:** Yes. At the top end of care there are a few clinics and schools around the world that use LEGO play in formal therapies and certainly many of the therapists I've met in Melbourne who use LEGO elements in their daily practice. We

are not trying to provide any formal therapies. We are trying to use the child's interest in LEGO play as a bridge to other people and a way of improving social skills. The spectrum is so wide and severity levels so different that we can use even the smallest thing to create opportunity for development. So just moving our door sign a few feet can challenge some kids who need routine. We try to think about the special needs of these kids in everything we do. We try to steer kids away from solo play and gently guide (those that can handle it) to interact with other kids. So for example bringing something that you have made may begin the step towards a conversation about it with somebody new. For more high functioning kids it is a chance to discuss the building techniques used or how much they love a new set. For these kids the challenge may be to take turns when talking and we try to role model appropriate conversations.

**Shelly:** You have a particular set of connections you look at for these sessions don't you?

**Rob:** My approach is based on strengthening three connections. Firstly there is the connection within the immediate family. LEGO building is something that the kid can do with Mum, Dad and siblings and there are opportunities to be pursued there to make family life better. Secondly we are aiming to make connections with peers so that they have a support group especially in preparing for difficult teenage years and finally if those connections can be achieved connecting to the community especially by displaying creations.

**Shelly:** You really think displaying creations is important don't you?

**Rob:** Yes it is a really very vital part in the journey. To display in a socially appropriate way is at the heart of the challenges that ASD people face. Displaying is about working with withdrawal, humility, and difficulties dealing with the "chaos" caused by other people's view points. It is not as easy as you would think to get an ASD child to work appropriately on a display. The simple act of putting a creation out for others to see is so rich with social nuisances that we take for granted. Taking and giving criticism appropriately is an area where higher functioning kids need lots of practice. Here is where we are trying to get them to think beyond just the model. So we think





about how will the other person see the model, how will you react if they really like it, what if they don't look at your model, what if somebody else wins the prize. That is why I encourage kids to bring something every session and set a theme each session to build towards. The theme also helps the family with focus and a shared goal each month.

**Shelly:** What has been the reaction to the ASD Aid?

**Rob:** I have been overwhelmed by people wanting help and to set up clubs and to find out about my approach. When I created a basic web site last year, within days I was getting request from people all over the world for information and I was also receiving hundreds of emails from researchers and therapists. Several wanted to know when our next training course was running so they could fly here to attend. I found that daunting and had to explain that I was just a bloke and a few mates not a big specialist clinic. From the parents there has been overwhelming praise and they love it. The kids live for the clubs sessions with many parents reporting improvements. They now have a focus every month that they build towards. Mum can also use that focus throughout the month to manage behaviours. And just like an Adult LUG these guys now have a group they can share their interest with.

**Shelly:** So what are the plans for ASD Aid now?

**Rob:** We have a solid base to operate from now and I really want to thank Amaze (Autism Victoria) for their help in connecting us to families in Victoria. That was vital in getting our first club operating. Now we are working to get some community groups organised so they can run sessions in their local areas. Our plan is to develop a few clubs and build up some resources that we can share with the rest of the community. We are also going to improve our web site to enable people around the world to register their interests or volunteer. Part of the plan is to enable people anywhere in the world to establish a club similar to ours. So we will build an action kit that Champions can access and start building a club.

**Shelly:** Is that where you see AFOLs helping out?

**Rob:** Absolutely. With tens of thousands of LEGO® fans worldwide we have the perfect base from which to spread the message about LEGO clubs for ASD kids. It is not hard to imagine AFOLs around the world championing a LEGO club in their local area. Just a few AFOLs and a handful of families can be a club. I don't want people to be put off by thinking they need some special qualifications. I would encourage people to just start talking about what they can do with a few impacted families and run a small session as a pilot. If you need ideas or want to register your interest to help out email me. I want

to hear about every club and help where we can. I may have been contacted by other locals from your area and can put you in touch with volunteers, donors or families who could use some help.

**Shelly:** Do you think these clubs will improve acceptance of ASD people?

**Rob:** My own attitude has really changed having seen lots of ASD kids at play. While low functioning kids have a daily struggle, I don't look at higher functioning kids and automatically think of them as disabled any longer. For me they just seem to have a "difference in being" that we need to accept and accommodate. Society needs to recognise that these special people are capable in their own way. Top researchers like Simon Baron-Cohen<sup>[7]</sup> and others look in non-judgmental ways about ASD behaviour. One of the things that has given me hope that we can change people's attitudes are organisations like the **Specialisterne**<sup>[8]</sup> (The Specialists). They are a company that provides a working environment where it is 'normal' to have ASD and they create the best possible working environment for special people. For example they can be outstanding at things like detail technical testing, quality control and data conversion work. Things others may find are chores are welcome and even satisfying job for a person with ASD. In the LEGO world for example a boy may really hate having to be involved in a school sport but he just loves sorting and classifying LEGO parts. Why force him to play football just because that is what all the other kids love? If we can show him how to use his interest, leverage his strength then work with others he can find a valued place in society. On a small scale, can you imagine how much LEGO there is to be sorted in a typical city? I am sure there are hundreds of Brick Link store owners and AFOLs who would love to provide work experience for people who love sorting. ASD Aid is trying to find these types of niches and connecting these people together so we can all "Play Well" together.

<sup>[7]</sup> [http://autismresearchcentre.com/docs/papers/2002\\_BC\\_ASDisability.pdf](http://autismresearchcentre.com/docs/papers/2002_BC_ASDisability.pdf)

<sup>[8]</sup> <http://www.specialisterne.com/>

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