Friendships, Belonging and Connection

Rob Last, CHARGE Syndrome Association of Australia and New Zealand

Presenter Information

Robert Last T.P.T.C. T.T.C.T.D. Cert.A AM. Rob Last is a teacher of the deaf who has a long history of working with children who have sensory disabilities, particularly in the areas of hearing and vision. Since the mid 1980's he has been particularly involved with children who have CHARGE syndrome and their families. He has been a presenter at the CHARGE Syndrome International Conferences since 1993, the Australian and New Zealand Conferences since 1994 and the German CHARGE Syndrome conferences since 2012. Rob is the Director of Outreach for the CHARGE Syndrome Association of Australia and New Zealand.

Presentation Abstract

Over the years in discussions with parents the topic of 'friendships' has arisen and the challenges children and young adults sometimes experience in developing and sustaining friendships. Often, apart from the family, it is the medical, therapy, early intervention and education teams who become the friendship circle rather than kids from the neighbourhood. In this presentation I will explore friendships, belonging and connection. This will include discussion on diversity and difference, self-esteem and confidence, peer acceptance, bullying, building capability and strategies for nurturing friendships at home and at school.

Learning Objectives

- Discussion surrounding difference and diversity.
- Strategies for nurturing friendships at home and at school.
- Issues surrounding bullying.

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Introduction:
In a recent CHARGE Accounts Newsletter, there was an article with the title 'A New Friendship'.
The family were attending the Orlando conference in 2017, without siblings, just Mom, Dad and Christian.
In the article the words connecting and belonging came up.
Mom wrote:
'Typically Christian prefers to stay on his iPad and not socialize, however this night we encouraged him to at least say 'Hi' and share his name with his peer group.
Quickly he met Andrew, another teenager with CHARGE. They had a lot in common – interests in 'How to Train Your Dragon' and 'iPads'. These two boys sat by each other and communicated through sign and their iPads. Their interaction was unprecedented and we decided that creating opportunities for their connection to grow would be the focus of our weekend.
Over the weekend the boys kept the connection alive'
and
'At the conference we always feel acceptance and immediately feel we belong.'

In my experience this is what occurs at all conferences, here in Australia and New Zealand and at the German conferences.

Belonging and Connections:
What's the difference?
Belonging relates to the symbolic spaces which feel familiar, comfortable and secure, and to which a person feels emotionally attached. We develop a sense of belonging over time, remembering experiences, people and places.
Connectedness refers to the quality and number of connections with people and place.

Key elements in helping a sense of belonging and connection are friendships, acceptance, feeling valued and capable, having supportive relationships and feeling safe and understood.

This describes these conferences.

In the beginning:
For people who have CHARGE syndrome, belonging and connectedness may develop very differently.
For young people who have CHARGE it is likely that the first friendship circle outside of the family will be the medical, therapy, early intervention and educational teams, rather than the kids from the neighbourhood. Connectedness may be with family; parents, siblings, grandparents and the medical and therapy team, which includes a range of doctors, occupational therapists, physiotherapists, speech therapists, nutritionists, special education teachers and more.

Once out of the medical environment the family remains the significant others and the home visiting therapy team may be seen as other primary connections. As we all know these are not the typical circles of friendships other children may experience.

Playgroup, preschool/kindergarten and school become the beginnings of new connections and in time a sense of belonging.

These friendships with teachers and therapists can be rich and rewarding and last for many years. For me I continue to be friends with kids I met in the first few months of their life, now in their teenage years, twenties and thirties.

Of course friendships with peers are most important and are to be encouraged and nurtured.

Diversity and Difference:
At these conferences, diversity and difference are commonplace with acceptance of difference being the norm.
I'm sure you all relate to the issue of people looking at your child in a different way. In talking with parents they describe the challenges;

'On good days it's OK, on not so good days it bothers me'.

Here at these conferences, we might no longer see the differences, however when we are out and about we may notice the responses of others and once again see the differences.

Being of different appearance may impact on the connections children make at preschool and school and when they are out in the wider community.
Their peer group and the general public may not be as unseeing.

However my observations of children with CHARGE in general is they don't seem to particularly notice or care about what others might think. However being of different appearance may impact on the connections children make at preschool and school and with the kids in their local community.

An interesting modification I've noticed in a young person I know well, she has modified her smile to a grin rather than smile broadly, as her facial palsy was more pronounced in a broad smile.

Turia:
To expand the concept of difference and diversity, I'll use the example of an Australian woman who was severely burnt in a grass fire while competing in a 100-kilometre ultra-marathon in 2011.
Her name is Turia Pitt. She has become an advocate for people who are of different appearance.

She is a superstar advocate for difference and diversity.

Her self-image is intact, self-esteem in place, has a pride in who she is and is a willing advocate for diversity and difference.

Also recent movies focussing on people of different appearance:
In 2017 I saw three movies all focussing on being of different appearance.
- Wonder - 2017

- The Shape of Water - 2017
- Beauty and the Beast – 2017

Building and Nurturing Friendships:
- Frequent, emotionally pleasant interactions need to occur and these interactions need to happen in a relatively stable framework of concern for each other.

- In the mainstream school environment where the student is in an inclusive program, the strategies the school has in place may be a buddy system, a mentor program, special interest groups, and support workers in the classroom, who encourage friendships.

- This is not the same as forming a friendship through common interests and the desire to develop a friendship through mutual engagement.

- For the student with CHARGE who doesn't hear all the nuances, can't see the details, misses the subtleties of facial expression and body language; which may result in confusion as to what is going on, not being able to keep up, feeling left out and perhaps giving up and withdrawing. For them forming and nurturing friendships can be a challenge.

Finding your tribe:
In the specialist school environment I've observed different outcomes. When students are with other students who have varying special needs it can seem like they have 'found their tribe'.

I attended a seminar on 'Facial Difference' where the speaker had significant facial difference.
She spoke of the importance of "finding your tribe".
At these conferences I see everywhere where the kids seem to have 'found their tribe'. Just like Christian and Andrew, whom I talked about earlier.

Throughout my career as an Early Childhood Educator
I was a strong supporter of inclusive education. In particular in the early years, during the playgroup/kindergarten/preschool years. In these educational environments the kids are surrounded by regular kids with regular behaviour, with regular speech and language, with regular play and regular expectations.
I advocated this for children of all abilities.
It was their chance to be with the local kids, to be part of the community, an opportunity to form local friendships, to be invited to local kids birthdays and also to be immersed in the regular behaviours of kids.

However I've had to rethink this in regard to the whole educational journey. Once embarking into the next stages of education primary and secondary school, the inclusive school program becomes increasingly challenging.
I've observed parents decide to begin with mainstream schooling, and at some stage in the school journey make the change to a specialist school environment, or to adopt home schooling.

Sean and Ethan:
In the specialist school environment I observed Sean and Ethan 'finding their tribe'. Sean followed mainstream education up until year 10, in year 11 he transferred to a specialist school.
Sean's literacy skills are age appropriate however the academic curriculum and managing the higher school education challenges were too great.
He and his parents made the choice to transfer to a specialist school.
Sean was involved in the process and was able to spend a couple of days a week at the specialist school to get a feel for it, to ascertain if this was going to be suitable for him.
Once full time at the specialist school he became school captain, voted for by his peers, and he found a good friend.
At this school he 'found his tribe'.

Strategies at school:
There are strategies to prepare the student and the school, no matter what school it may be.
- Orientation to the school. Several visits prior to commencement. School needs to be a familiar and safe place.
- Orientation to the school staff. They need to be knowledgeable on

the challenges of CHARGE syndrome and familiar with the student.

- Involve the student in all the school commencement process.
- Highlight the skills and interests of the student: communication, academic, personal, social, recreational, leisure, sport, hobbies and community involvement.
- Encourage a buddy system.
- The aim is for the student to:
  Feel capable. This applies to academic achievements and non-academic achievements.
  Feel valued. This is being appreciated for the qualities that the student brings to individuals and the wider school community.
- Encouraging involvement in common interest groups.
- Finding the supportive students and adults at school.
- Nurture connections when they occur.
- Encourage initiative and independence.
  This is trusting that students have the capability to manage their social times with autonomy whenever they choose, this may be with other students or may be by themselves. At other times they may need the support of an adult.
  It may be a mix of both.
- Circle of Friends
  Circle of friends is an approach to enhancing inclusion in a mainstream setting of any student who is experiencing difficulties in school through disability, personal crisis or challenging behaviour towards others.
  Check this out on: inclusive-solutions.com

Strategies at home:
In 2017 I spoke about focussing on 'passions' and to then use the 'passion' to find those who have a common 'passion', which may result in developing social connections and friendships through common interests.

- Notice the passion, nurture the passion, and embrace the passion.
- Find individuals, groups and clubs who have the same passion.
- Use the passion as an educational opportunity and as a possible employment opportunity.

Thoughts for parents:
These apply to the transitions from home to educational settings and to changes in educational settings: home to preschool, preschool to

primary school, primary school to secondary school, secondary school to tertiary education, secondary school to employment options.

> For parents it's about:

- Networking, perseverance, research, positive outlook, assertiveness and finding the energy.
- An ability to advocate the student's strengths, gifts and talents.
- An ability to describe the students needs, challenges and supports required.
- Considering and describing the ideal school/work day for the student.
- A clear understanding of what is not acceptable for the student's future.

More tips for parents:
YouTube clip with Zach Anner
Zack's four tips:

- Be OK with watching your kid struggle.
- Raise your kids to be considerate, thoughtful adults who aren't always the centre of attention.
- Be careful about accidentally patronising your kids.
- Let your kids passions lead not the disability.
- Treat your disabled teenager like a teenager.

Bullying:

- The research shows children with disability experience more bullying than peers, regardless of age, educational setting, gender or type of disability.
- Establish the school policy on bullying.
- Having a trusted adult, parent, teacher and/or friend as someone to report to about any bullying being experienced.
- Use students who have been bullied to educate other students about bullying prevention.
- Friends give a 'wall of support' and protection.

Time alone:

- One of the many things I admire in people with CHARGE is their ability to appear comfortable in their own space.
- To spend time alone doing what they like to do.
- To not seek lots of social experiences.

- We may perceive them as feeling lonely but this may not be how they feel.
- Give permission and allow for time alone.

The Internet:
- Researchers are increasingly recognizing the potential of the Internet to provide social and emotional support to various groups that share a common goal, identity or experience.

- For some the Internet is the most effective tool because they are spread across the globe and frequently not mixing with other children within their immediate community.

- The Internet, therefore, provides a central meeting places for those who are unable to regularly meet with similar others at a single geographical location.

- Benefits of online communities include increased recognition and acceptance from others, reduced social anxiety, reduced isolation and strengthened social support networks, and a greater acceptance of one's own identity.

In conclusion:
This a short story about belonging and connecting told through pictures.

- Cassandra and Sean met at a picnic.
- They hadn't met before but connected quickly and easily.
- It was time for lunch.
- Their lunch was prepared.
- Cassandra realized Sean's lunch was just like her lunch … via
- G tube.
- They enjoyed this experience very much.
- Sean's arm crept around Cassandra's, connection and belonging was complete.

In addition:
There are many pathways in establishing friendships, belonging and connection.
For many of you it's one of the reasons you are here.
For those of you new to conferences, I hope you also find it here.

Thank you
Rob Last
Email: roblast@iinet.net.au