

EXPERIENCE COLLIDER

EVALUATION REPORT

November 2019

- Associate Professor Jenny Downs
- Ms Nada Murphy
- Ms Amy Epstein

Artwork by Nada Murphy

Telethon Kids Institute,
Perth, Western Australia



FOREWORD

As a paediatrician and child health researcher, I don't need any convincing about the benefits of the creative arts to child development. We know that a broad range of stimuli help to maximise cognitive, emotional and physical function, particularly making the best of the developing brain.

And there is plenty of evidence around the specific benefits of exposure to, or even better participation in, the creative arts. So a few years ago, this nexus between child development and the arts made me jump at the opportunity to become patron of the Awesome International Arts Festival for Bright Young Things in Western Australia. As a sometime amateur thespian, I also love the exposure that Awesome gives me to some incredible performances.

So to see the *Experience Collider* appear on the 2019 Awesome Festival program was an extra pleasure. This initiative is truly revolutionary and incredibly ambitious – not just taking teens with high support needs to see the circus, but actually having them participate and perform. Seeing the teens from CircusWA working alongside the teens with high support needs in a range of circus performances, involving specific skills in circus, dance and sound, was a true delight. And what a great idea! The circus is a highly diverse and stimulating environment, encompassing artistic and other creative skills together with demanding physical requirements. Surely no part of the brain gets to rest when participating in the circus!

The evaluation performed by researchers at Telethon Kids Institute confirmed what was obvious to the observer at the performances, that *Experience Collider* brings great benefits to the teens with high support needs across a range of domains. But there is more – the Circus WA teens also experienced great satisfaction with their participation, and a greater awareness about working with teenagers with high support needs.

I send my hearty congratulations to all involved in making Experience Collider happen.



Jonathan Carapetis

Executive Director, Telethon Kids Institute

Patron, Awesome International Festival for Bright Young Things.



EXECUTIVE SUMMARY

Cultural development organisations DADAA and CircusWA established a partnership and developed the idea for a circus program integrating young circus performers and teenagers with high support needs. This joint circus program would culminate in a public performance blending the creativity and enthusiasm of young people across a spectrum of differing abilities. With the support of funding by the Channel 7 Telethon Trust, *Experience Collider* was born; a partnership which was then extended to include researchers at Telethon Kids Institute, who conducted a formal evaluation of the impacts of participation in *Experience Collider*.

Individuals with disability can live with functional challenges such as mobility and communication difficulties, as well as restrictions in being able to participate in social and community activities. Support needs are variable. High support needs involve multiple domains and for the current project, was defined as difficulties in three of the communication, behaviour, mobility and social domains. These can challenge the achievement of good quality of life (QOL). Despite these difficulties, environmental supports can enable more positive functioning, mental health and social interactions together with a strong QOL, despite severe disability. Establishing ways to mitigate the disadvantages of disability with high needs, where disadvantage is more substantial, and enable strong and thriving QOL is an important target.

Creativity and the arts, including circus, dance and physical theatre, can contribute to better wellbeing for children with disability, effects that are amplified by inclusive participation. To our knowledge, there are no documented examples of an evaluation of an inclusive circus intervention aiming to enhance participation and wellbeing in individuals with high support needs.

Experience Collider was designed for 13 to 18 year old teens with high support needs to engage with and learn skills in circus, dance and music alongside teens from CircusWA, delivered by professional creative artists. The program ran over an 18 month period and culminated in three performances that were held in the State Theatre Centre of WA on 4-6 October as part of the 2019 AWESOME festival.

This report presents the evaluation of the impacts of *Experience Collider* on the QOL of teenagers with high support needs. The evaluation framework involved 1) interviews with artistic staff at the outset to consider their goals, expectations and aspirations for the teens, 2) direct observation of program activities, 3) multiple evaluations of QOL over the course of the program, and 4) repeat interviews with artistic staff to capture their reflections on the successes and challenges of *Experience Collider*.

The artistic staff considered and tested a wide range of activities to identify possibilities that would ultimately be integrated into a performance, all the time working to establish relationships with the high needs teens. Sessions included CircusWA teens, increasingly as the program progressed, to build collaborative capacity, with ownership of the activities belonging to all teens. Over the course of the program, the responses of the teens with high support needs during activities were overwhelmingly positive, illustrating enjoyment of physical activities and social interactions in particular. At times, the teens with high support needs experienced emotional and behavioural challenges, but their internal drive and interest supported by the building of relationships and teamwork together with the CircusWA teens enabled solutions to be found. Focus during activities increased over the course of the program, thereby facilitating longer practice of routines and enabling the performance.



Researchers also measured QOL at multiple times throughout the duration of the program. At each assessment, the primary caregiver reported on the QOL of the teens with high support needs over the previous month, capturing life outside of the program. These assessments found that QOL increased over the course of the program, with total QOL scores increasing on average 22.7 points on a 100 point scale. This effect was also observed for the domains that specifically explored the teens' physical health, positive emotions and the variety of activities that they engaged in. The positive behaviours observed during the program sessions were accompanied by additional QOL benefits outside of the program in daily life.

After the final performance, artistic staff reflected as to the program's strengths, challenges and surprises. Establishing effective relationships and communications was the fundamental platform for success, and these tasks required commitment from both staff and teens. This enabled growth in the circus skills of the teens with high support needs in order to successfully perform live alongside a troupe of CircusWA teens. The CircusWA teens and parents provided additional feedback that illustrated their satisfaction and joy in achieving artistic and personal outcomes alongside the high needs teens.

This project has several implications for teens with high support needs and circus performance more generally. The teenagers with high support needs demonstrated capacity to develop new abilities within a complex creative environment. CircusWA teens experienced growing awareness and understanding of communication and working with teenagers with high support needs, and this social engagement was important to the success of the program. The collaborations of teenagers with high support needs and those from CircusWA in an inclusive performance allowed each performer to challenge the notion of elite models for creativity. The *Experience Collider* program had flow on effects for the teens with high needs and was associated with better QOL more broadly than just when attending sessions.

This evidence supports the importance of running similar creative projects in the future for individuals with high support needs, who currently experience disadvantage in and barriers to accessing community projects and events. Future funding will be essential to 1) build and maintain the infrastructure of available artistic expertise and 2) deliver innovative and creative programs providing opportunities for community participation.



Copyright Telethon Kids Institute



INTRODUCTION

Background

Approximately 15% of Australian children live with a disability. Many of these children experience difficulties with the conceptual, social and practical skills necessary for daily living, often with intellectual disability [1]. Children who are more severely affected have multiple support needs, likely experience difficulties with mobility and communication skills, [2, 3] and many will have additional health problems such as epilepsy, scoliosis and poor sleep [4, 5]. With more health challenges, many children experience more hospitalizations than typically developing children [6]. Other children experience challenging behaviours [7] and some live with mental health problems [8]. *These contribute to restrictions in being able to participate in social and community activities and each health and participation factor can adversely affect the child's quality of life (QOL).*

Despite difficulties with health and functioning, care and supports can optimise health and build capacity for functioning, particularly in the communication domain. With an effective means of communication, individuals with severe disability and high support needs can clearly demonstrate their own choices, express enjoyment and develop productive relationships with family and peers [9]. These observations are consistent with the notion of the *disability paradox* [10], that environmental supports can enable more positive functioning, mental health and social interactions together with a strong QOL, despite the severity of disability. *The imperative is to seek ways to mitigate the disadvantages of disability and enable strong and thriving QOL for children with disability.*

Quality of life

QOL refers to satisfaction with the composite of life experiences and includes domains that are universal (eg, health, emotional wellbeing) with additional domains for particular populations [11]. We recently undertook four qualitative studies to investigate the domains of QOL important to children with either cerebral palsy, Rett syndrome (a severe genetic neurodevelopmental disorder mainly affecting females[12]), autism spectrum disorder or Down syndrome [13-16]. QOL domains were consistent across the four disability groups. Whilst some domains such as emotional wellbeing mapped broadly to other QOL measures, many elements were unique to our subject group [13-16].

We therefore constructed a new QOL measure called the Quality of Life Inventory (QI-Disability). QI-Disability comprises 32 items each rated on a 5-point Likert scale with six domains identified using factor analysis: Physical Health, Positive Emotions, Negative Emotions, Social Interaction, Leisure and the Outdoors, and Independence [17]. When assessing individuals with high support needs, multifaceted outcome measures such as QI-Disability are necessary to assess practice and novel interventions. *QI-Disability has the potential to measure responsiveness to interventions that would aim to increase QOL.*

Participation

As defined by the International Classification of Functioning, Disability and Health, participation is "involvement in a life situation" and can be operationalised as attendance and involvement [18]. Participation activities can be informal or structured, they can occur at home or in the community, and can involve recreational, sport, arts and social activities. The elements of meaningful participation include having fun, experiencing success, belonging, experiencing freedom and learning [19]. Children with intellectual disability typically participate in more activities at home and fewer community leisure activities [20, 21], with smaller social networks than their typically developing peers [22].



Participating in meaningful activities at home, at school and in the community is important for children to support their physical, cognitive, social and emotional development: participation is therefore a key contributor to strong QOL [23]. Children with disability who participate in physical activity have demonstrated gains in aerobic capacity, strength, endurance, competence and confidence [24]. However, the effects of other opportunities for community participation have been less well investigated for individuals with high support needs, who historically have faced greater physical or social barriers to community participation [21]. *Opportunities for participation within learning and social environments for people with high support needs, including in sports and artistic activities, are desperately needed.*

Creativity, the arts and wellbeing

Multiple studies illustrate how participation in arts interventions contributes to better physical and mental health, creating meaning in life and empowerment and reducing physical and mental health symptoms [25]. Using qualitative methods, the acronym CHIME, representing Connectedness, Hope and optimism, Identity, Meaning in life and Empowerment, was derived from the data to describe the human processes of recovering mental health [26].

Research also suggests that arts participation of people with disabilities is associated with better health and wellbeing. The playful and creative self-expression found when engaging in art and drama can help to restore emotional balance and to renew focus on achieving strong QOL, supporting the creation of a healthy community [27]. For example, a theatre-based intervention for 8 to 12 year old children with autism was associated with reduced stress and anxiety as well as growth in social competence, attributed to the development of close collaboration within the group of actors [28].

Social circus

Social circus is one of the many categories of circus practice and involves a community-based arts program aiming to create social transformation for vulnerable groups [29, 30]. In the first instance, social circus provides recreation and extracurricular activities to individuals for whom participation in opportunities could be restricted. Second, social circus supports an agenda of social change [29, 30]. *Social circus as such is seen as an effective way of engaging with vulnerable populations and increasing QOL within education, physical activity and creative frameworks.*

There are examples in the literature of how participation in social circus activities have created positive opportunities for individuals with disabilities. For example, young adults with physical disabilities were able to participate in a social circus program, and before and after interviews indicated personal strengthening of confidence and self-perceptions as well as greater participation more generally in communication, mobility, relationships and community activities [31]. For example, a circus training program has been developed for children and teenagers with autism in Queensland (<https://www.circusstarsasd.com>). *To date, there are no documented examples of the application of a social circus intervention to enhance participation and wellbeing in individuals with high support needs.*

Inclusive participation

Opportunities for *joint participation* by children who are typically developing and those with disability can be readily created within arts activities and interventions. Typically developing children would have opportunity for the development of understanding, friendships and empathy for developmental differences, both physically and conceptually, which can have important implications for building positive social attitudes [32], alongside their learning of the arts based skills.



Children with disability would have opportunity for skill building, performance and the development of new social relationships supported by the engagement of their typically developing peers. There are some examples in the literature. For example, a young 11-year-old girl with Down syndrome was supported to engage in a production comprising acting, voice and dance, and this was associated with gains for her QOL [33].

The current project

This project was conducted by DADAA and CircusWA. The program was called *Experience Collider*, blending dance, circus, and music with a performance outcome. It was created for young people with disabilities to work with leading professional artists. Its creative journey is described and illustrated in a blog (<http://experiencecollider.dadaa.org.au>).

This report describes the evaluation of the implementation and effectiveness of *Experience Collider* as a positive experience for participating teenagers with high support needs within a QOL framework.



METHODS

Study designs

Researchers conducted a process evaluation comprising four phases, to maximise our capacity to document implementation and effectiveness of the program within a necessarily small sample size. Several study designs were used in four phases of evaluation.

1. **Phase 1:** *Qualitative interviews* were conducted at the beginning of the intervention program to explore the initial expectations, strategies and experiences of the artistic team in planning and the early delivery of the program.
2. **Phase 2:** *The behaviours of the teenagers with high support needs were observed* during the development of the program and coded according to QOL domains.
3. **Phase 3:** *Questionnaires* were administered to the teenagers' primary caregivers to collect QOL data at several time points over the course of the program.
4. **Phase 4:** The *qualitative interviews* with the artistic staff were repeated after the final circus performance to allow staff to reflect on the achievements and challenges they had experienced and to recommend future strategies for program implementation. Additional feedback was provided spontaneously by the CircusWA teens after the final performance and were also documented.

Ethical approval was provided by The University of Western Australia (RA/4/20/4569).

Participants

The 15 teenage participants were aged 13 to 18 years (10 males) and had high support needs in at least three of following four domains: communication, behaviour, mobility and social interaction domains. An occupational therapy assessment was conducted to establish the presence of high support needs and indicate eligibility for the study. Table 1 presents the distribution of the levels of functioning for speech, mobility, hand function and socio-emotional regulation for high support needs across the participating teenagers.

Table 1: Distribution of levels of functioning for the 15 participating teenagers with high support needs^a

Speech ^b	Some sentences and phrases	2
	Single words	3
	Vocalisations and signs	8
	No spoken words	4
Mobility	Independent walking	4
	Assisted walking	5
	Unable to walk	6
Hand function	Difficulty with tasks needing dexterity	9
	Unable to grasp objects	5
Socio-emotional	Some difficulties regulating behaviours	5

^a Comorbidities such as epilepsy, scoliosis, hearing loss were identified for 11/12 teens.

^b 11/12 teens with speech difficulties had a communication support device.

Seven teenagers trained at the DADAA site on weekends and during school holidays, and eight teenagers trained with the artistic team during the week at their school site. Each of the parents of the teenagers participating at the DADAA site provided consent for data collection in relation to their child and these data are summarised in this report.



The artistic team members who participated in the interviews conducted in Phase 1 and Phase 4 included the artistic director, a circus artist, two dance artists, a composer/musician and a circus director.

Program

Working directly with the teenagers with high support needs at both sites, the creative team facilitated new ways of performing. Activities were conducted individually, in small groups and as the larger performance group. These activities were tailored to individual capacity including repurposing of traditional circus tools such as trapeze, silks and stilts, and additionally included aspects of dance and theatre. The program built skills through a series of workshops. Collectively, the activities enabled the participants to overcome obstacles and circus apparatus was reconfigured to create a unique visual spectacle.

The teenagers with high support needs trained as part of a broader ensemble of young people that included teenagers from CircusWA without disability. A key theme for this program was the sharing of experiences and challenges, to foster the growing of relationships between individuals with and without disability.

The program was conducted over an 18-month period enabling the participants to develop a final performance. The teenagers attended classes each week at DADAA and The Freo Big Top in Fremantle. The program could be divided into three stages:

1. Familiarisation, exploratory, skill building - May 2018 to March 2019.
2. Performance preparation of sequences - April 2019 to September 2019.
3. Rehearsal and performance of the work at the AWESOME Children's Festival - October 2019.

Evaluation procedures

PHASE 1: Initial qualitative study

Interviews with members of the artistic team were conducted at the beginning of the program. Questions investigated how the artistic staff were structuring the program to achieve individual and group goals, challenges that were encountered and their expectations. The interview schedules were semi-structured with key topics covered using core questions, and additional probing questions followed new lines of questioning and sought additional detail. Interviews were audio-recorded and transcribed prior to thematic analysis. The interview schedule is shown in Box 1.

Analysis: A grounded theory approach was used where themes were fully informed by the data rather than any pre-existing theory or framework, enabling key themes to evolve naturally from the interview transcripts. Coding was subject to constant assessment and contrasting of different ideas and observations as new data were analysed. To fully understand the dataset, transcripts were read and re-read by NM and AE and data were then coded using NVivo (International Pty Ltd: Burlington, MA, 2014). Themes as well as elements within the themes were ascertained. Three researchers (NM, AE, JD) reviewed and interpreted the themes and coding within the transcripts. Joint discussion was then used to establish a consensus of the primary themes and elements within themes.



Box 1

1. The first group of questions is about preparing for your performance. What are the first steps in planning a program?
 - a. How is the program then introduced to the group?
 - b. How do you decide what types of activities are best suited to each teen?
 - c. What is your process for making adjustments to the program?
 - d. What are you hoping the teens will gain from their involvement in these activities?
2. When everything is going great in the program, what sorts of things are happening?
3. When things are not going so well, what sorts of things are happening?
4. What sorts of activities are largely successful?
5. What sorts of activities are often challenging?
6. Now let's talk about your vision for the program.
 - a. How will these activities evolve over the next year to become the final performance?
 - b. How will this performance build or shift our perceptions of the art?
 - i. For the teens?
 - ii. For the audience?
7. Personally, what has it meant to you to be a part of *Experience Collider*?
8. Are there any other aspects of the program that you would like to talk about?

PHASE 2: Observations of teenager behaviours

Programming during each of the sessions was variable at the discretion of the artistic director with new activities introduced over time. The observational sessions were of varying durations and the duration of individual activities within the sessions varied from approximately five minutes, particularly at the beginning of the program, to approximately 45 minutes, particularly towards the end of the program. Both observers (NM, AE) have postgraduate training in psychology.

An observational method was designed to describe and code participant activities during the sessions. A coding framework for the observations was developed to reflect the activities using select domains identified as important for the QOL of children with high support needs [17]. The domains in the coding framework included Variety of Activities, Social Interaction and Independence, and the Positive and Negative Emotions domains were collapsed to one coding domain. This coding framework documented direct observations of observable events that would indicate that the participants experiences were either enhancing or threatening their QOL at that moment. Target domains are presented in Table 2.

NM and AE used narrative recording to document the actions and behaviours within each sequence of activity. Each action and behaviour was allocated a domain code and direction (positive or negative for Social, Emotion and Physical domains). The codes were summed for each participant and tabulated. The coding system enabled activities, reactions and involvement to be described and quantified.

Observations were collected on 17 of the total 51 (33.3%) activity days at the DADAA site, spread across the different stages of the intervention (22 sessions were conducted at the school site).



Table 2: Observational coding domains and their working definitions.

Domain	Coding symbol (positive or negative)	Working definition
Social	S+	Doing activity with others in the group or in pairs. Engaging with a communication partner with talking, making eye contact, listening, paying attention, using physical gestures to communicate.
	S-	Looking away from main activity. Being solitary. Interactions that had negative impact.
Emotion	E+	Showing pleasure, smiling, laughing.
	E-	Showing distress, withdrawal, anxiety, displeasure.
Physical	P+	Participating, practicing or copying a physical action.
	P-	Not participating or demonstrating that a physical action is not manageable.
Independent behaviour	I+	Doing a task or behaviour without assistance. Self-initiate introduction of a new action. Showing persistent effort without assistance. Showing a personal preference or making a choice.

Analysis: Vignettes were documented and are presented verbatim. Because of the variable durations of sessions and activities, rates of observed behaviours could not be reliably estimated. Therefore, the number of positive and negative observations for each domain were summed for each participant at each session. The percentages of positive and negative behaviours overall were then calculated and shown graphically by time. The percentages of positive behaviours in each domain as a percentage of all positive behaviours were graphed to illustrate the components of sessions over time.

PHASE 3: QOL data collection

Parents of teenagers attending the DADAA site were invited to complete the Quality of Life Inventory-Disability (QI-Disability) on multiple occasions from baseline at entry into the program until the final circus performance. Questionnaires took approximately 10 minutes to complete and were administered in multiple formats including web-based or on paper to enable optimal participation.

QOL data were provided by six parents (86%) on two to four occasions, providing longitudinal time-series data. Linear fixed effects models were used to assess the relationships between time and the QOL total and domain scores (Physical Health, Positive Emotions, Negative Emotions, Social Interaction, Variety of Activities, Independence), adjusting for teenager age at baseline. Data analyses were undertaken using Stata version 16.0 (StataCorp, College Station, TX).

PHASE 4: Follow-up qualitative study

The qualitative study was repeated soon after the final performance to capture the reflections and recommendations of the artistic team and the interview schedule is shown in Box 2. Again, themes were identified and relevant text was extracted to illustrate the themes.



BOX 2

1. What do you see that the main gains were from delivering the program?
 - a. Teens with high support needs?
 - b. Would you like to comment on the CircusWA troupe teens, audience and others as well?
2. What sorts of activities were successful and what are challenging?
3. What would you do again in a future program?
4. Are your expectations for children with high needs different to how you felt at the beginning?
5. What was the main thing you came away with as an artist yourself?



RESULTS

PHASE 1: QUALITATIVE INTERVIEWS

Three themes emerged from the data describing Artistic Expression, Establishing and Maintaining Relationships, and Processes and Program Adaption.

Theme 1 - Artistic Expression: Prior to the commencement of the program, artistic staff were open to new possibilities in building a performance, through exploring a range of mediums of expression including movement, imagery and tactile experiences. This theme included three elements: use of multiple media to provide *auditory and instrumental experiences* (using a variety of instruments and devices to make sounds), *visual imagery experiences* (including drawing in space with bodies, using technology to create interesting images), and *props and tactile experiences* (including the use of physical objects brightly coloured or pleasant to touch). Two of these elements are illustrated with a relevant quote.

1. Visual imagery experiences

“Creating a drawing with the idea that art is accessible to everyone and that what their capacity is just about how you engage with the concept of drawing. And so some people will be drawing in space with their bodies and other people might be drawing using technology and other people might be drawing – it all comes together in an image or a picture, which also then doesn’t necessarily mean it needs to fit a story or a spectacle but... it still holds interest, it still has a quality of its own, because we’re all contributing to this image.”

2. Props and tactile experiences

“Objects, actually introducing physical objects into the space, so things that are brightly coloured or tactile, nice to touch, and then by holding on to that and asking them to hold on to that as well, we can discover how they want to move with that object or play with that object.”

Theme 2 - Interpersonal Relationships: This theme referred to the building of supportive relationships, establishing trust between participants, exploring a variety of communication options including gestures and physical means, and developing an understanding of participant interests. Strategies for engagement included accepting brief attentional focus and whatever participants might offer by way of movement, sound or other responses to activities offered by artistic staff. This theme included three elements: finding *physical connections* (developing trust in playing, holding and supporting each other), *social connections* (looking, listening and asking questions) and *effective communication strategies* (using body language, facial cues and expression).

Physical connection

“One of the older circus kids was working with [a high support teen] ... and they were playing and falling together onto the big crash mat, and rolling, and doing some tumbling. And just that trust between them, that they could do that safely together and that it was fun. And it’s a really lovely thing seeing an equal amount of satisfaction, to see [the circus teen] having as much fun as [the high support teen] was really wonderful.”

Social connection

“We have had one of the young kids fly up to one of the [high support teen] participants and stop, look for a while, listen and then say Can you understand me? And then actually started to talk directly to that person, so asking that person the question rather than the person standing next to them. So, some of those moments have been quite moving.”



Communication ability

"I think with almost every single one of them there's been at least one moment where an offer or a task or a game or a prop might be met with silence. And so sometimes it's hard to know because most of them are non-verbal or verbal communication is very limited, that sometimes the silence is just processing for them and we have to really be very patient and just wait and kind of see if the silence is thinking about it, is it either they're evaluating for themselves, assessing Am I interested in this thing? or have they actually just started daydreaming and they're thinking about something else entirely different. Or the silence is because they're not comfortable, they don't want to interact with that theme, so we have to sort of wait and try to read the facial cues or the body language. So, there's definitely times when we have to check and we're not sure. And so, then if it goes on for long enough that there's sort of the silence or nothing's really initiating from them, then we'll offer Okay maybe we'll try something else. And then sometimes it's also because they're tired, so they actually just need a break. But getting them back into being interested can sometimes feel like it takes 10-15 minutes with uncertainty."

Theme 3 - Process and Program Adaption: The artists discuss the notion of program development and envisaged that they would adjust activities to suit participant capacity and interests, ensuring accessibility of activities, program ownership and teamwork, all the time aiming to build audience involvement. Elements included: relating to *participant-directed activity* (responding closely to any involvement of the participants), *staff-directed activity* (adjusting tasks to overcome obstacles, regular dialogue between workshop leaders), *creating high levels of participant ownership over the course of program development*, and confidence in developing a performance that will engage participants.

Engagement of participants

"I think when it's going well, we have the attention of the room on a single point... and that doesn't have to last for a super long period of time. But when you know you've got them, even if that's for 30 seconds at a time and everyone's focused on that, I think that's really powerful."

Participant-directed activity

"We are also responding quite closely to anything that any of the participants are giving. So, if this kid starts to do a running motion, Oh, let's do that. Ah there is a story happening here. One of the high support needs kids does a particular move or makes a sound, then there is a response to that action and to that sound."

Staff-directed activity

"We'll always attempt to adjust the task before choosing to stop doing it altogether. But it might be just that the prop that we're using is not accessible to everyone, or the space that we're in doesn't work best for that activity. We'll always try and find a way around the situation, but then it's also quite easy to say okay let's just move on and try something else. So, there's always an ongoing dialogue between the workshop leaders. And particularly because we've got a close eye on everyone all the time and how they're coping with each exercise. We need to be constantly in negotiation of that."



Program development

“I’m interested in creating a work that the young people can have a really high level of ownership of, and when they present it they do so in a way that is really confident and high-level exchanges are on display amongst the ensemble, and that the experience of performing is very positive. Ultimately, we are talking about the value for the audience, but a lot of our performance is the value of the performers attaining that level of interaction and teamwork, the realisation of their artistic vision. So, for me it’s about facilitating that, that experience, and when we get the audience involved, I’m hoping that they feel like they are close to the experience. So, it’s kind of an intimate spectacle paradox. It feels quite impressive and highly developed, but it’s still live and nearby and being created in front of them.”

PHASE 2: PARTICIPANT OBSERVATIONS

1. The first stage of the program comprised familiarisation, exploration of interests and engagement, and the building of skills. During this stage, teens were introduced to novel activities, modification of activities to incorporate participant responses and any limitations, providing the participants with video feedback, exploring communication options, building relationships and groups ownership of the process.

Engagement in the program was observed to require participants to be in close physical proximity to others and with some participating in physically demanding activities such as building a human pyramid. Where a participant was limited in physical movement and communication, participation may have included amplification of soft vocalisations. Pleasure and enjoyment were shown with subtle facial expressions, squeals of delight and other vocalisations.

Some physical activities demonstrated not only a participant tackling a physical challenge, but the building of trust that eventually enabled a productive team outcome. In moments where the participants were observed to experience distress, artistic staff embraced fluidity in their direction to maintain creative engagement and re-establish engagement. The following vignettes illustrate key components of stage 1.

Activities:

Enjoyment of physical interaction between artistic staff and participant

- *Ashton is working on a small rolling platform large enough to hold him and Bernie. They lay across the platform and move around the room. Ashton is comfortable with the physical contact he has with Bernie and pushes himself along with his feet. He slips off at one point and promptly recovers his position, climbing back onto the platform. He is smiling and making soft sounds and seems relaxed. He puts his hands to his mouth once. In all, he seems to really enjoy being able to move on the rolling platform, the action of pushing the platform around, and the physical contact he has with Bernie.*

Enjoyment of exploratory activities

- *Mohammed is invited to join the circus teens on the mat for warm up exercises and rolling from one end of the mat to the other. He participates in this activity very well, follows the actions of others and copies different actions. He shows some hesitancy and looks to his carer (for reassurance possibly) and only loses concentration briefly. There are very few idiosyncratic behaviours, such as head shaking, hand waving and flicking, which only interrupt the activity momentarily. Mohammed shows appreciation for the skill of a circus teen doing cartwheels and enjoys rolling in the silk.*



- *Hugo engages with Bernie in shadow play. He is attentive to the shadow and makes shapes by raising his hands. Bernie makes her shadow push his shadow. He responds as if this hurts by saying "Ouch" and makes growling sounds. He uses his shadow to make his shadow hit the other shadow back!*

Interest in activities involving cooperation

- *Sam invites Edie up to the pyramid. She smiles, laughs and puts her foot on Sam. Nel helps her up onto the pyramid. Edie seems very happy, smiling at Nel. Nel holds her in the pyramid and she remains very happy. Sam says, "Stay there". Edie looks around and joins in climbing. She touches Sam's hand and bends over as Nel steadies her and holds her legs. Sam takes a hold on Edie's hand. She is giggling and climbs up and looks around. Everyone else sits in a circle as members of an audience. Edie is quite excited and very happy in this activity. Leila as audience is interested and initiates socialising with one of the circus teens.*

Exploring communication, preparing for use in activity routines

- *Evan shows interest in the camera and projection, and he enjoys making sounds which are amplified by the mic. He has momentary shifts which may be due to poor control over his head movement. He is happy to interact with the CircusWA teens and with Sam.*
- *Leila appeared to enjoy having control over and making choices using the communication book. She remained engaged throughout this activity.*

Dealing with discomfort or distress:

- *Edie was becoming distressed. The trigger was not clear. She was unsettled by something and began to cry and made moves to leave. Nel and Sam comforted her and she returned with Nel to sit and watch the group. She joined the activity again for a brief time before withdrawing and choosing to move a chair to the rear of the room. Sam responded by calling this a picnic break, improvising with chairs and rugs on the floor in the rear area of the hall. This meeting time was used to talk about being a team and included play with bean bag juggling balls. Edie was very pleased with this development and participated well and was happy again. She ate her lunch whilst the others played.*

Physical challenges

- *Ashton appears to be willing to work with Sam with different movements until he is rolled over. He appears to experience some discomfort and does not take up on the prompts to join in, instead curling up on the floor. He looks tired. Initially he does not seem to want to engage in the activity with silks but after a time, grabs the silk and begins to experiment with Sam, using the silks before curling up on the floor again. His father helps him to his feet, he falls back into a seated position and moves toward the teens, accepting the gesture from a CircusWA teen who placed the silk over his face. He seems to enjoy the activity and watches the teens working above on the silks accepting also Nel's gesture offer of a silk which he pulls over himself. He makes soft sounds suggesting he is relaxed and vocalising some pleasure. He joins in with the microphone activity feeling the sound vibrations before accepting more slide activity combined with the silks.*

2. The second stage of the program comprised preparation for the final performance. During this stage, participants began to work collaboratively with staff and the CircusWA teens to develop performance sequences that served as the basis for the final production. This involved working under the direction of staff to rehearse and refine the sequences, responding to cues and learning how to behave when off stage and waiting for their call. The contexts were more demanding as



there are sequences to follow and often multiple parallel activities going on in the tent. There was focus on the development of relationships with fellow performers, safety, building capacity for sustained effort and greater flexibility to recover from upsets. The following vignettes illustrate key components of stage 2.

Increased complexity in activities

- *There are parallel activities. Troupe with Laura including Leila is working a sequence of moves to make a body sculpture on the mats. The sequence is rehearsed a couple of times. At the same time Hugo and one of the CircusWA teens are working in the centre of the tent under the ropes. The CircusWA teen is suspended and Hugo is positioned underneath. They work in tandem with Nel instructing.*
- *Mohammed is asked to join in the warm up group. He seems mostly engaged and happy although has some shifts in attention. Mohammed works with Sam and Nel on the hoop after watching Caleb. He enjoys the interaction and is laughing and smiling. After a short while, he tumbles out of the hoop onto the crash pad, a short distance. He seemed to initiate the move to the ground out of the hoop.*

Practice of components of the performance and following directions

- *Caleb is a motivated teen. In the brief time he has participated in the program, he was involved in all activities. Caleb follows Leila's idea to 'reverse clap', starting with both hands together silently and then separates them quickly apart to each side. He follows directions from staff closely and with eye contact. He offers minimal verbal communication unless asked a direct question, but his receptive understanding is high and he follows Leila's instructions to snap, clap, etc. Caleb is open and willing to try all of Leila's suggested moves e.g. handshake, touching wrists and elbows.*

Developing sequences of activities

- *Hugo is required to drive through a human bridge. He is pleased to be asked to do this move. He makes a number of moves independently to take up his starting position and then and drives his chair through the bridge. He has only a momentary lapse in attention but otherwise is concentrating on the directions given. He appears to be anticipating his moves and becoming familiar with his role.*
- *Leila is rehearsing a new move using the hoist with two CircusWA girls. The move requires her to take both a standing and sitting position in the hoist whilst the hoist is being pushed, and then to swap place with the CircusWA teen who sits in the hoist and does an acrobatic routine. She works cooperatively. At first getting into her position seems difficult. She communicates through touch to draw her attention to task and works cooperatively with her fellow CircusWA performer to push the hoist whilst another teen performs acrobatics in the hoist. The move is rehearsed then filmed, Leila then initiates the change in her position from standing to sitting and directs the other teen to take her turn. Leila smiles and frequently make sounds of pleasure.*
- *The Train Move; four CircusWA teens take position on the mats on their hands and knees in a tight formation that provides a support for Ashton to be carried. Ashton gets up and walks to the train, taking large steps suggesting he is keen to participate. He goes on his hands and knees like the others and rocks. He works in close physical contact, laying on the top of the teens who move forward together. Sam supports him. He starts to fall then climbs onto his feet and resumes his position. The group do a second rehearsal. Ash appears calm and relaxed accepting the physical support and interaction with the others.*



Communicating with the group

- *Edie gravitates to a fit ball, batons and juggling ball as well as glove play. She puts large rubber gloves on and seems keen to engage in activities with the artistic staff. Two of the CircusWA teens try to engage her in the activity with them but she does not take this up and goes back to Laura. She initiates a number of activities of her own accord and the staff create activities with these things which Edie seems pleased to do. She hands over the gloves as she leaves and says goodbye to the group, despite her earlier hesitancy to interact.*

3. The third stage of the program comprised rehearsal and refinement of sequences of performance. Each participant was asked not only to be ready to take their cue but also be quiet audience in preparation for the expectations on stage. Teamwork and communication skills were more evident, increased focus and attention was necessary and tasks were more physically demanding. The following vignettes illustrate key components of stage 3.

Teamwork and pleasure in achievement

- *Hugo and his CircusWA teen partner perform their sequence with the CircusWA teen suspended on the rope and connecting with Hugo below. The sequence involves the circling when connected and Hugo raising his chair to be at the same height. Hugo shows pleasure at doing the performance smiling at the audience and in particular when he had completed the upward movement of his chair, although he also checks downwardly as he does this. Leila in the audience expresses pleasure in watching*

Communication

This vignette illustrates how the participant connected vocally with the performers and staff who noted his responses and were able to provide further opportunities for him to communicate.

- *Evan observes the others and then it's his turn. He makes breathing sounds which get recorded. Gives eye contact to Sam who is holding the microphone. His face moves to the microphone, lips move up and down and eyes look towards Sam. He turns towards the sounds beside him as the CircusWA teen also makes noises into the microphone and he follows her with his eyes. The microphone comes back around to Evan, his lips move, and his sounds resume - he adjusts his head and blinks his eyes. Some discussion between staff about whether blinking means 'yes' but this is not completely clear. Evan's head and eyes orient to Sam as he moves around the room.*

Breathing sounds are played back to Evan. He moves his head while listening to the sounds. He appears engaged in playback, where all sounds are being mixed together with reverb by Roly. Evan is lifting his right hand in the air as he listens. His head tilts slightly. Sam introduces the "rain tube" instrument. Evan rotates his head and moves mouth to the sounds. Sam supports Evan to then hold the tube, generate sounds, and allow Roly to record his sounds. His left arm loosens to allow for rotation with Sam supporting it.

Evan orients his head towards the circus teen generating new sounds into mic. He makes gurgling vocalisations, tilts his head while listening. Evan attends to Nel's mouth noises which sound like various animals. He turns his head towards the sounds that interest him and appears curious about them.

When it's Evan's turn again, he brushes the mic with Sam supporting his arm and hand. The sound is recorded, and Evan appears to smile and indicate he is happy with this activity. Evan laughs and smiles while his carer comes back to readjust his arms and push him further back in the seated position in his chair.



Teamwork and anticipation of roles within the sequences:

- *Hugo and the CircusWA teen work as a team under Nel and Bernie's direction. The move involves Hugo manoeuvring his chair in a circle whilst the CircusWA teen swings in the air connected to the chair. Hugo takes the direction to go to his position to start the move and follows all the directions given him. He manoeuvres his chair smoothly into the desired position until the release when he is to exit to the right. Strong illustration of peer engagement and support.*
- *Sam works with Evan and the circus teen to rehearse the move involving the teen and Evan holding hands whilst the hoist and chair are moved in a circle and then move is reversed. Evan is engaged and relaxed, smiles, moves his head to look and follows the teens lead. The moves are repeated. Evan enjoys holding on and moving with the teens. He shows a good understanding of what he is to do, raising his arm in anticipation of the teen performing on the hoist. An additional move, involving two CircusWA teens supporting his arms and back, pushing him forward and then reversing, is rehearsed. He remains calm and accepting of the physical contact, and keeps focus looking at the other teens he is working with. Again, he shows pleasure in completing the hold, circling move with the teen on the hoist. Compared with earlier observations, when Evan sat quietly and showed only small smiles, there is clear evidence that Evan is moving more of his own accord, albeit small gestures, but certainly showing enjoyment with big smiles and enjoyment watching his acrobatic CircusWA teen partner perform together with him.*

Relationships and specific communications

- *Leila enters the tent and gives everyone welcome greetings by smiling, waving at staff, and with eye contact. Leila initiates hugs and signs to carer.*
- *Evan sits with Bernie and a CircusWA teen. Initially he watches. Then he has to role of being in charge of the activity called "Switch". Evan use eye movement to choose the next activity from a panel of pictures. He is sitting upright and moves his head and hands in the air, engaged in the process.*

Safe practice within the circus context

- *Nel and Simone bring Mohammed in to have a short session on the hoops. He is assisted in the moves and shows he is enjoying the activity a lot, laughing and smiling. Simone and Nel work with him to ensure he is safely engaged as he goes to disengage himself twice, but follows direction, he then stays put and thereafter accepts the assistance.*

Sustained attention during physically demanding tasks

- *This session commences with the group doing warm up exercises with Laura on the mats. Caleb sits on the floor with the rest of the group taking her direction for most of the exercises, stretches, jumping, finger exercises and warming up the body.*

Caleb then moved to the hoop to work with Nel and one of the CircusWA teens. This was an extended practice that involved a series of moves that are rehearsed several times. He showed he was able to hold himself in position within a hoop suspended with a silk from the supports above crash mats, his head supported by the rim holding to the rim above him and with feet place opposite knees bent whilst he is spun. He seemed calm and focused throughout and sustained the activity to complete up to 7-8 revolutions of the hoop at one time. The next sequence required him to shift a position with his feet on the bottom rim of the hoop. Nel prompted him in ways to make the move safely using both hands and Caleb



demonstrated he had the strength to pull himself up onto the silk. He was then directed in how to change position to “fall into the hoop”.

Caleb achieves this position as well. The whole three parts of the sequence were rehearsed and then performed for the rest of the group who give him a rousing applause. Nel says “Good job, excellent. You have worked hard for a rest” This session lasted almost an hour and demonstrated multiple skills including physical capacity, ability to sustain attention and follow directions.

- *Leila is ready in position on the hoist with the two CircusWA teens she is working with. She is excited and takes her position in the hoist independently, placing her feet securely on the lower bar and following the CircusWA teens signal for her to place her hands securely on the top of the frame. The two CircusWA teens then push Leila into the centre where she then changes to a second position without being prompted, which was part of the sequence, and is pushed again. She then takes her position at the back of the hoist as one of the CircusWA teens takes her position in the hoist and with the second teen pushes the hoist back into the centre. The teen in the hoist starts to spin and Leila helps the spin by pushing. Her enjoyment throughout is evident by squeals of delight and smiles both in anticipation and during the teens hoist performance and the completion of the sequence. The move demonstrates that she is able to work with a series of moves in close collaboration with her fellow performers and her pleasure with the process.*

Recovering from upsets, illustrating resilience and determination

- *Edie comes into position to climb up onto two teens, their legs in position to make a pyramid. She begins to climb on cue but hesitates, gets upset and begins to cry and gets down again. She is comforted by Simone and stops crying. Sam encourages her to try again, showing her the move again. Edie then tries again by placing her feet in position, accepting the support and contact with the others to hold her place. The audience applauds before she stepped down. Simone gives her a big hug. The sequence shows that Edie is keen to participate and was able to regain her composure in order to try again what is a very challenging physical task.*
- *Ashton is working with Nel and a CircusWA teen (Storme) being pulled around in his chair, one person on either side, for a sustained period of about 40 minutes. This includes stretches and later the “slow freeze” where teens on the floor move and then make contact with each other. His interaction with his collaborators is attentive throughout. He has minor lapses in attention.*

Observational coded data

Most of the vignettes illustrated positive behaviours and this was reflected in the quantitative data also. A total of 2,528 behaviours were observed, of which 2,248 (88.9%) were positive and 280 (11.1%) were negative.

This proportion was observed consistently in each of the stages across the duration of the program, as shown in Figure 1, as demands and complexities of both tasks and the environment increased. The sessions earlier in the program involved short activity sequences, often with just high needs teens present and with girls sessions being run separately from the boys sessions.

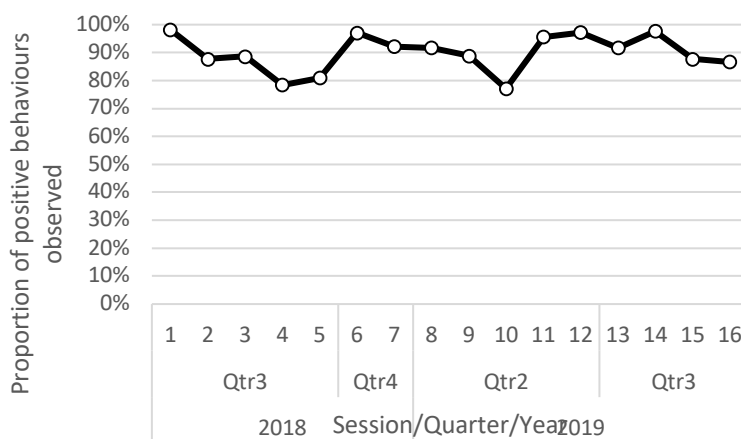
Progressively, teen activities were in combination with CircusWA teens culminating with the troupe assembling to develop performance sequences before rehearsals of the whole show. The lowest



points on the graph reflected some of the teens experiencing difficulties such as noted in the vignettes.

Without any normative data regarding how typically developing teens might be expected to behave in such circumstances and given expected lapses in attention and fatigue, the observations suggest that not only did the teens overcome their personal challenges but they mostly maintained a high level of positive behaviour throughout the program.

Figure 1. Trend of proportions of positive behaviour observed during activity sessions in teens with high support needs who participated in the *Experience Collider* projects at the DADAA site.



Of the positive behaviours, the proportions of behaviours coded in each of the domains were similar across the duration of the program and in each of the stages. More behaviours illustrated pleasure in Physical and Social Interactions than in Emotions and Independence domains (Figure 2).

Figure 2. Trends of positive behaviours observed, proportions by domain during activity sessions in the teens with high support needs who participated in the *Experience Collider* projects at the DADAA site.

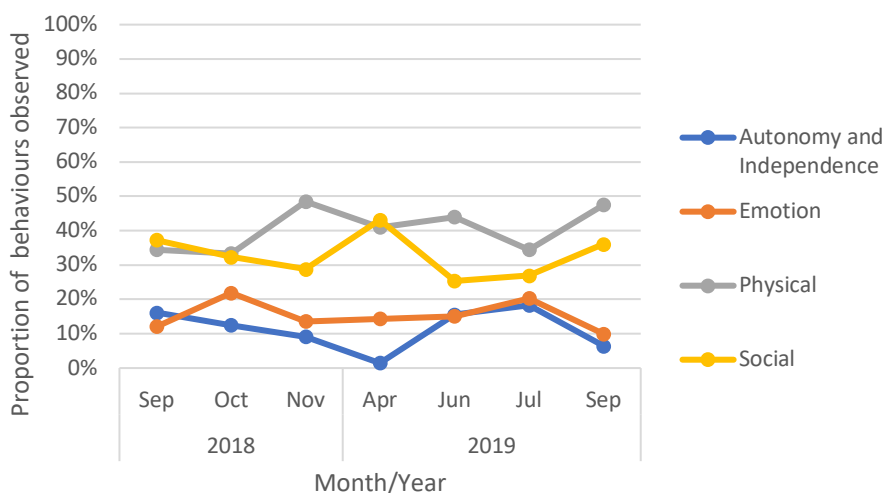


Figure 2 above illustrates a predominance of positive physical responses which related to the development of performance skills and being attentive and ready, as you might expect in a circus program that aimed to elicit these behaviours. There was also clear evidence of positive participation in the activities involving interactions with others, including paying attention, watching others and turn taking.

Less frequent but also evident were expressions of positive emotions which included not only smiling but also displaying a calm manner. Behaviours that showed some level of independence and initiative to instigate activities through expressing curiosity and interest in the materials and activities on offer were also observed.

PHASE 3: QUALITY OF LIFE QUESTIONNAIRE DATA

Twenty sets of QI-Disability data were collected from the primary caregivers of six of the seven DADAA participants, a median of 3.5 (range 2-4) times each. The age of the participants at baseline was a median of 16.0 (range 13.8 to 18.9) years. At baseline and out of a total score of 100, the mean (SD) total QOL score was 67.2 (14.6). The mean (SD) values for the domain scores are as follows: Physical Health 65.6 (24.2); Positive Emotion 69.8 (20.7); Negative Emotions 74.4 (16.0); Social Interaction 69.6 (22.7); Variety of Activities 65.0 (19.0); and Independence 60.0 (23.0).

The total and domain scores increased steadily over the 18-month program, and changes in the total and Physical Health, Positive Emotions and Leisure and the Outdoors domains were statistically significant (Table 3). Compared to baseline, the *total score* increased 7.6 points per 6 month period with an average gain of 22.7 points at the end of the program. Compared to baseline, the *Physical Health score* increased 12.8 points per 6 month period with an average gain of 38.3 points at the end of the program. Compared to baseline, the *Positive Emotion score* increased 9.7 points per 6 month period with an average gain of 29.0 points at the end of the program. Compared to baseline, the *Leisure and the Outdoors score* increase 11.5 points per 6 month period with an average gain of 34.4 points at the end of the program (Table 3). There were more modest increases in the Negative Emotions and Social Interaction domain scores, and Independence domain scores did not change. These trends are also presented in Figures 3 and 4.

Table 3. Estimated change in QOL scores (total and domain) from baseline per 6-month period over an 18-month period, adjusted for age at baseline, in six teens with high support needs who participated in the *Experience Collider* project.

	Total	Physical health	Positive emotions	Negative emotions	Social interaction	Leisure and the outdoors	Independence
	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)
Time since first interview (6m)	7.6 (3.4,11.8)	12.8 (5.5,20.0)	9.7 (10.0,15.6)	5.0 (-3.4,13.3)	5.6 (-1.9,13.2)	11.5 (1.8,21.1)	1.9 (-7.3,11.0)
Age at baseline, years*	1.0 (-2.2,4.3)	-1.7 (-6.8,3.4)	0.3 (-4.8,5.4)	-1.7 (-5.3,1.9)	2.1 (-2.0,6.2)	1.2 (-3.1,5.4)	6.8 (1.8,11.9)
Constant	68.7 (58.4,79.0)	62.1 (45.7,78.5)	70.4 (48.9,91.8)	70.3 (58.0,82.6)	73.8 (58.3,89.2)	67.5 (52.7,82.3)	66.2 (53.2,70.4)

Coef, coefficient; CI, confidence interval



* Age at baseline was centred at the overall median age of 17.5 years. The median age at first interview was 16 years (range 13.8-18.9 years, inter-quartile range 14.4-18.6 years)

Note: Longitudinal data were fitted using generalised linear model (Gaussian distribution with identity link) with the generalising estimating equations (GEE) approach. An exchangeable working correlation was used to model the within-group correlation. The Huber/White/sandwich estimator of variance was used to compute the standard errors of the effects. The average number of interviews per individual was 3.3 (range 2-4).

Figure 3: Trend of QOL total score over the 18 month program.

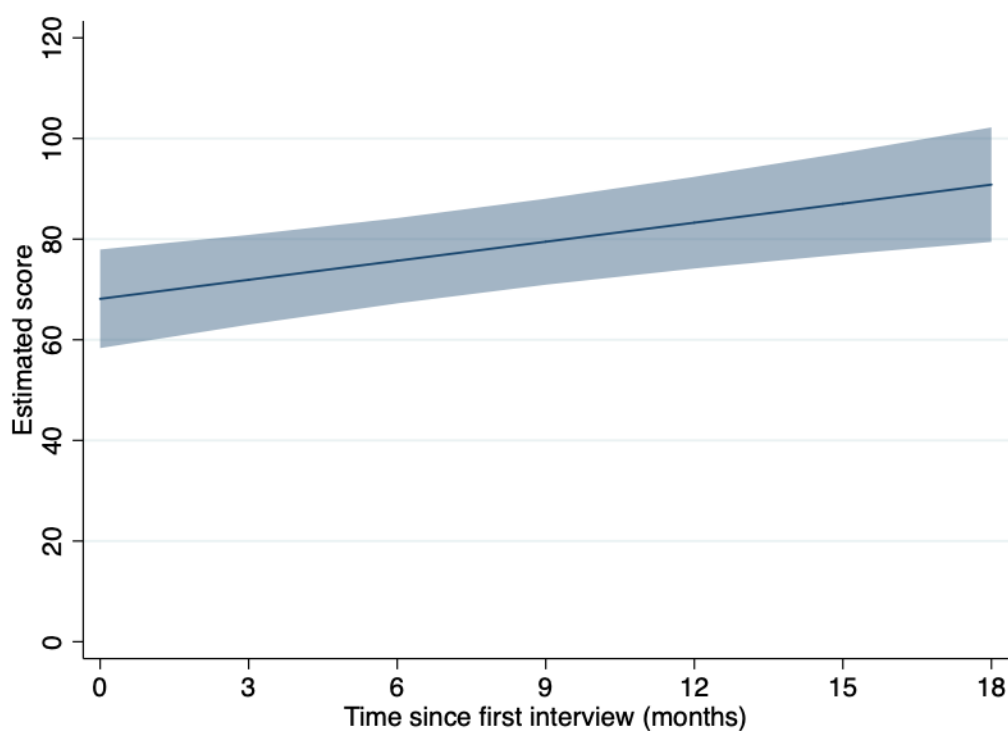
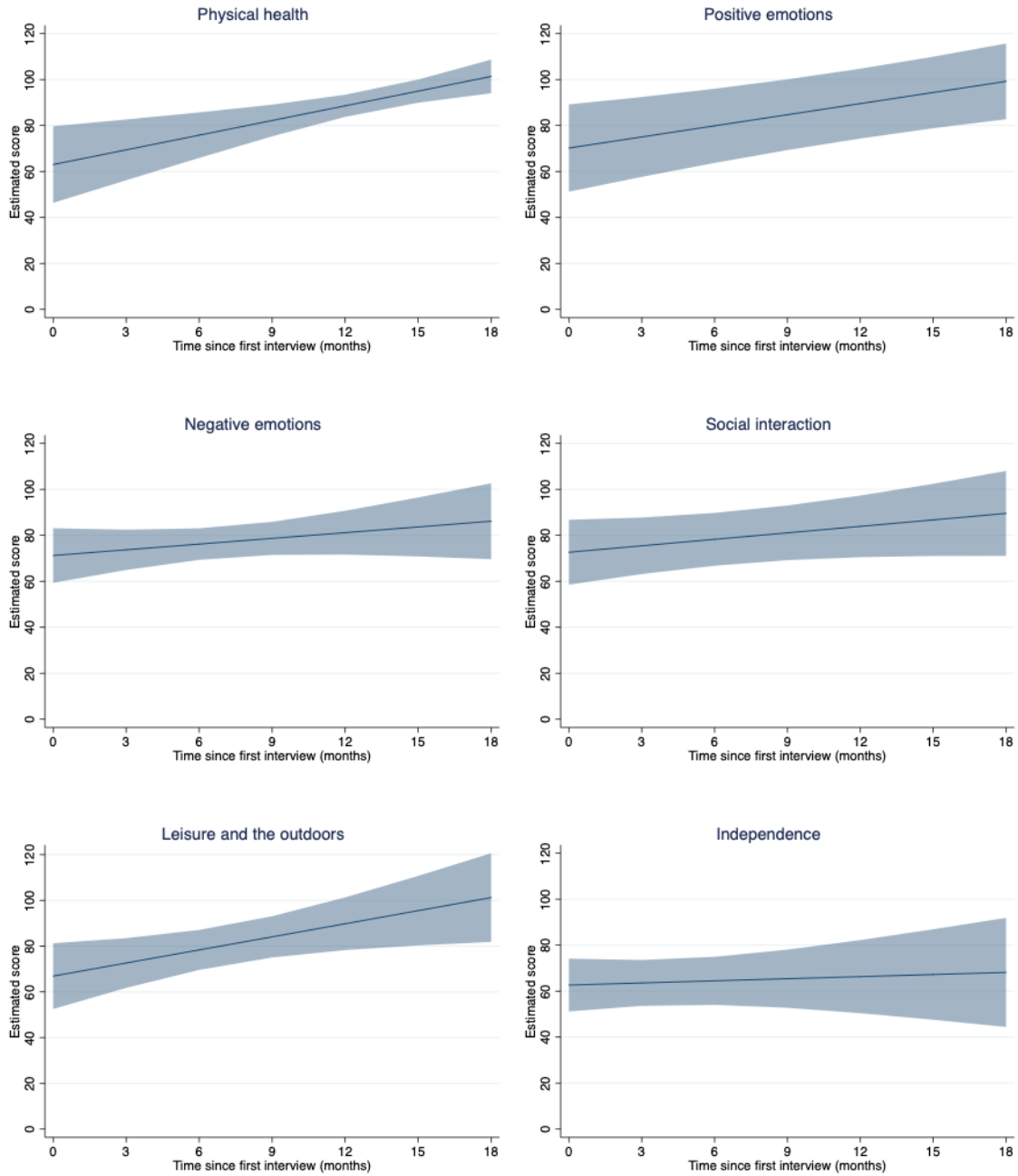


Figure 4: Trends of QOL domain scores over the 18 month program.



PHASE 4: REPEAT QUALITATIVE INTERVIEWS - POST-PERFORMANCE REFLECTIONS

The program culminated in the final *Experience Collider* performance. Three performances were held in the State Theatre Centre of WA on 4-6 October 2019, a powerful demonstration of inclusive performance where each artist on the stage was able to showcase their learned skills, talents, enthusiasm and openness to possibilities.

Post-performance reflections were collected from the same six artists who participated in the Phase 1 evaluation. Staff described how an important aspect of the program was its duration, giving time to the development of effective relationships and communication systems. This was the platform for the development of growth in capacity of participants, a strong inclusive framework, and opportunities for fun with unexpected joyful things.

Theme 1: Relationships and communication - The development of relationships was critical to the progress of the program, between the teens with high support needs, CircusWA teens and artistic staff. Staff reflected how these had been characterised by trust, teamwork, conversations involving all of the crew and providing emotional support to each other. This formed the platform for careful coordination of creative activities, such that activities were paced whilst maintaining engagement across the ability levels.

- *“The biggest benefit for the performers with high support needs was that they really became part of a social group. A strong social group that involved people without disability their age, and it was really genuine, and the connections were strong and genuine. I think the journey of the Circus performers is quite important in that they also became invested in this group that you don’t see in the everyday very often. Participants were wanting to stay in contact. In terms of how I have seen people with disability yearn for social inclusion and social equality particularly amongst teenagers this cannot be overstated.”*

Evidence of positive relationships and communication were evident also in activities to the side of internal artistic works. At one point, one teen was becoming unsettled and one of the CircusWA teens just walked over, helped him to calm and thereafter to engage in an enjoyable activity. Other important opportunities for social engagement were during activities such as lunch breaks.

- *“The sitting down and watching each other feed. Watching someone get peg fed. Watching someone put food over their face and watching them sitting and eating, so that was a shared space. The everyday spaces were also successful and important in that it is not just about work, it’s about building up a relationship. That is true for any creative development, any team development, that sharing food and sharing social space, builds teams.”*

Theme 2: Growth and capacity of teens with high support needs – Abilities to stay engaged mentally and physically grew over the course of the program. At the outset of the program, artistic staff did not know what was possible and invested in understanding their personalities and preferences, and physical skills. An occupational therapist provided advice on safety aspects regarding activities involving wheelchairs and hoists, and safety was a consideration with each new activity. The development of new physical skills including using circus equipment that enabled aerial work with harness support was particularly successful with one routine also being included in the performance. With time, more and more activities were created and tested, beyond initial expectations.

- *“So, you know that if you just keep trying, attempting new ways you will find something eventually even if it takes a long time. Eventually you will find a way in.”*



- *“I don’t think there can really be progress unless there are setbacks along the way that are then overcome. Like in any kind of psychological journey, then you come across these enormous stumbling blocks.”*
- *“But this was no different to working with the CircusWA teens – whilst there were restrictions in some areas, the teens with high support needs could be stretched in many ways. And that was quite magical.”*

Theme 3: Engagement of CircusWA teens - Experience Collider provided many novel experiences for the CircusWA teens, experiences in working with peers with a larger range of abilities over a long project time frame. Artistic staff were aware that this was new for CircusWA teens and sessions were characterised by a culture of communication, collaboration, teamwork and skill building. The integration of the different components to form a performance was ultimately inspiring for the CircusWA teens.

- *“To the credit of the circus performers they really did learn to work slowly. There were long rehearsals for kids that age , because we couldn’t work in a short time. The time and being generous and not using too much language was really amazing that they bought into that.”*

Theme 4: Unexpected joyful things – Some skills that were developed were beyond initial expectations.

- *“Mohammed taught himself a forward roll that week . He was always rolling but he taught himself a straight forward roll just by observing his CircusWA teen partner for the activity. And when we got to the theatre, he just started saying his name, I think it was the second day.”*
- *“Edie was kind of a catalyst for everyone to get excited and realise how important that week was and that time together. Her mum said that the second day she was so excited that she woke her up first thing in the morning and handed her black clothes to her mum and was just rearing to go like “Let’s get to the theatre”. And she didn’t even hesitate to walk into the green room with everyone. Her mum said to us that the theatre was like a cocoon, she felt safe and we really saw her social skills comes to life that week.”*
- *“Hugo heard the C and he played the C. What if I give you a G? I am not saying the word, I am playing the note and he gets it again. So I turn the guitar neck away so that he cannot see what I am playing. I turn the guitar away and play something - a C# and Hugo takes a second, he moves a little bit to the side so he can reach the note and goes “bang”, and he hits the exact note. And every time. I was just astounded. It is always a surprise that someone has a unique ability. We put it in the show that night. And you could hear the audience gasp. It speaks to what the project is about. We do expect less than we do of ourselves, so when it turns out they can do the same as us we are quite surprised. We don’t even imagine that they can do something better than us.”*

The artists were unanimous in their enthusiasm to mount a future show. Everyone maintained that the process was sound and that future shows would be different because they would reflect on the contributions and growth of the performers.

The artistic team were also unanimous in their support for the effective way in which the Artistic Director had led the process. Options for how each artistic discipline could contribute were



explored. Time spent in preparing for each workshop and post-workshop reviewing was considered essential to the success of the project for building a cohesive approach within the artistic team and allowing for a variety of approaches. A positive by-product for the artists was opportunity to additionally develop their own artistic processes and skills, necessary to deliver such a project in a flexible and adaptable way that challenged conventional arts practice. Each discipline was valued for its unique contribution: Dance brought sensitivity to communicating without language; Music set an emotional tone and provided more opportunity for nonverbal communication; and Circus comprised multiple approaches to explore physicality.

Each artist agreed that the final week leading up to the performance and the performances exceeded levels they thought possible at the beginning of the program.

Other reflections from the CircusWA community:

Both the CircusWA teens and their parents also reflected on their experiences with an all abilities program. Each response illustrated the importance of understanding how life is for others, learning and collaboration, and how creativity is an important key to allowing different contributions to be artistic and inspiring. See examples in Box 3 and Box 4.

Box 3

Given its name sake, the *Experience Collider* project was exactly how one would expect it to be; an experience. As a young abled artist, any opportunity to express myself through physical performance is a gift; so when I was offered to be involved in a production that was going to be different from any other that I'd participated in before, I was instinctively curious. I recall the first few rehearsals as "odd, creative and beautiful." To be encouraged to move through interpretation and improve was extremely new to me and I'll admit a struggle. However, I was motivated by collaborating with artists that didn't share the same abilities as myself but possess the epic capability of imagination, wonder and inclusivity which provides one with such gratitude and a fresh perspective for possibility.

Eighteen months only seems like eighteen months when you look back. Nonetheless, you sub-consciously feel such time weighing on you when creating a production; particularly when you must establish relationships with your cast and crew as the standard language of verbal communication is distorted into something that fits everyone. The motivation can lag, the desire to continue is tiresome and the effort starts to run low. I felt like this some way into production, I had external priorities and wants that outweighed the desire to pursue a position as a member of the cast. In spite of my doubts, one day during rehearsals I looked around the cramped tent and noticed the sense of connection. The team that surrounded me was working for something greater than all of us. A purpose to break down barriers. In times of selfishness I remember that moment, the moment that told me that art is a communicative tool to teach and inspire; why wouldn't I want to be apart of something like that.

The performance week was a wicked ride. I personally feel like it was a period of true connection between everyone involved with the creation of *Experience Collider*. The work was direct yet required attention, teamwork and effort. The days were long but incredibly well spent and every show was rewarding. It felt right for all performers to have a stage to express their own stories, potential and skills. It was simply, wonderful.

I must give thanks to the creative directors Sam, Bernie and Laura as they opened the door of true contemporary art for myself and many of my fellow cast members. I've learnt things that will forever impact how I see the world and how I perform as an artist, my deepest gratitude. The cast was an unexpected teacher of mine, my peers taught me the power of connection; which is profoundly apparent in inclusivity.

Experience Collider has been a privilege.

CircusWA teen



Box 4

Experience Collider has certainly been an unforgettable journey for my daughter.

From the very start of the concept she was engaged and excited about what lay ahead. It has been beautiful to hear her talk about the new friends she has made, for her to see how life is for others, and to understand that everyone has something enriching to share.

I think that it has been great for the ensemble to witness the show come together organically and to be a part of the entire creative process. It also has to be said that putting the show in a theatre setting with the lighting, videos and sound was amazing and added to the whole experience.

My daughter has said that she hopes there will be more involvement with the DADAA kids in the future, she was definitely sad when it all came to an end.

I hope that she has taken in all of the teams creative wisdom and will embrace what she has learnt with a renewed confidence for her year ahead. For us, it was clear to see that despite age or ability there was a shared love of what was being created, everyone was respectful of each other, everyone was learning from one another and the ensemble had some amazing role models and mentors. So great to see something where everyone is the star!

Parent of a CircusWA teen



DISCUSSION

The *Experience Collider* program was designed for teens with high support needs to learn skills in circus, dance and music alongside teens from CircusWA's youth troupes, supported by DADAA and CircusWA staff, and then to present the work as a public performance. Participation of the teens with high support needs was mostly characterised by positive functioning, mood and social interactions and by the end of the program, each individual with high support needs was able to achieve a high level of performance ability. This included playing potent roles that were clearly personally satisfying, and within a very polished and professional production with their CircusWA peers. Session effects spilled over to everyday life with stronger QOL more generally as the program progressed.

The *Experience Collider* program illustrated how circus can be a platform for development of a vulnerable population in parallel and together with the development of a young and vibrant existing circus troupe. High support needs involves difficulties in multiple domains and for the current project, was defined as difficulties in three of the communication, behaviour, mobility and social domains. As such, the program was consistent with the goals of social circus which include support so that participants can achieve personal and social development by nurturing their self-esteem and trust in others, teaching social skills, and helping them to express their creativity and explore their potential [34]. The artistic staff considered and tested a wide range of activities, extended their own artistic scope to identify possibilities that could ultimately be integrated into a performance, and all the time worked to establish relationships with the high needs teens. Sessions included CircusWA teens, increasingly as the program progressed to build collaborative capacity, and with ownership of the activities belonging to all teens. CircusWA teens experienced growing awareness and understanding of communication and working with teenagers with high support needs, and this social engagement was important to the success of the program. *Experience Collider* was an inclusive program.

Over the course of the program, the responses of the teens with high support needs to activities were overwhelmingly positive, illustrating enjoyment of physical activities and social interactions in particular. At times, the teens with high support needs experienced emotional and behavioural challenges but their own internal drive and interest, and the building of relationships and teamwork, together with the CircusWA teens, and the flexible creative approach enabled solutions to be found. Focus during activities also increased over the course of the program, enabling longer practice of increasingly challenging routines to facilitate a performance. We developed a method of direct observation for this project and captured behaviours on one third of the sessions. We acknowledge the difficulties of coding complex activities involving multiple individuals and we calculated percentage values to quantify behaviours because of the differing time frames. Our methods could be further developed with interval recording and reliability checks, but these two steps were beyond the scope of this evaluation. However, we are confident that together with the descriptive vignettes, we have captured a balanced estimate of session content that demonstrated highly favourable growth and participation in the program.

We measured QOL using a validated scale [17] at multiple times across the program period. At each assessment time, the primary caregiver reported on their child's QOL over the previous month, capturing life outside the program. QOL increased over the course of the program with total scores increasing on average 22.7 points on a 100 point scale. This effect was also observed for the subscales measuring physical health, positive emotions and variety of activities. These data suggest that the positive behaviours observed during the program sessions were accompanied by additional QOL benefits outside of the program sessions. We estimate the magnitude of change to be large



and important. Establishing ways to mitigate the disadvantages of severe disability and enable strong and thriving QOL is an important target. This finding taken with our direct observations indicated that *Experience Collider* was an important vehicle for achieving better QOL.

Artistic staff reflected after the performance on the program's strengths, challenges and surprises. Establishing effective relationships and communications was the fundamental platform for success, requiring commitment from staff and all teens. This enabled growth in the circus skills of the teens with high support needs in order that they could perform live with a troupe of talented CircusWA teens. The CircusWA community provided additional feedback that illustrated their satisfaction and joy in achieving alongside the high needs teens. The acronym CHIME represents Connectedness, Hope and optimism, Identity, Meaning in life and Empowerment, and was created to represent aspects of the processes of mental health recovery in adults, a pathway achieved using arts interventions [26]. The artistic staff played a critical role in facilitating each of the CHIME components during *Experience Collider*, supporting the capacity of the teens with high needs to make gains in their participation and wellbeing in a community context where the principles of equity and health were the focus.

A limitation of this evaluation is that we do not have the voices of the teens with high needs, beyond direct observations of their enjoyment or challenges. We commenced use of two picture boards, supported by Julia Hales. One picture board illustrated activities (positive – it's fun, it's awesome VS neutral/don't know VS negative – it's not fun, it's boring) and the other illustrated emotions (positive – happy, excited VS neutral/don't know VS negative – sad, worried) – to ask the teens to describe some of their experiences. This is a work in progress and these methods need further development. Collection of responses from the high needs teens would likely need to use devices other than picture boards to yield useful data. This is an important project for further research.

To our knowledge, there are no documented examples in the peer reviewed literature of the application and evaluation of an inclusive circus intervention to enhance participation and wellbeing in individuals with high support needs. The implications of *Experience Collider* for teens with high support needs and circus performance are many.

1. The teenagers with high support needs demonstrated capacity to develop new abilities within a complex creative environment, beyond expectations and stereotypic values.
2. Language was not essential to participation.
3. Creativity and the performance arts, including circus, can contribute to better wellbeing for children with disability, effects that are amplified by inclusive participation.
4. The high needs and the CircusWA teens collaborated together, had equal roles on stage and each performer grew and challenged the notion of elite models for creativity.
5. The *Experience Collider* program had favourable flow on effects for the teens with high needs with better QOL more broadly than just when attending sessions.
6. This evidence supports the importance of running such creative projects in the future, and the need for essential funding to
 - a. build the infrastructure of available artistic expertise and
 - b. deliver innovative new programs.



ACKNOWLEDGEMENTS

We extend our heartfelt thanks to the many individuals who developed and contributed to *Experience Collider*, which was a privilege to evaluate.

We particularly thank

- All of the teens with high needs who attended the DADAA and Kenwick school sites, and their families.
- The CircusWA teens who committed to *Experience Collider* for the duration of the program, gave their skills, support and friendships, and made critical contributions to an exhilarating inclusive performance.
- Associate Professor Helen Leonard for reviewing the initial proposal and Dr Kingsley Wong for supporting data analyses.
- Ms Judy Lariviere and Ms Julia Hales for supporting the initial steps in seeking the voices of the teens with high needs.



Copyright Telethon Kids Institute



REFERENCES

1. Leonard, H., et al., *Prevalence of intellectual disability in Western Australia*. Paediatric and Perinatal Epidemiology, 2003. **17**(1): p. 58-67.
2. Colver, A., C. Fairhurst, and P.O. Pharoah, *Cerebral palsy*. Lancet, 2014. **383**(1474-547X (Electronic)): p. 1240-1249.
3. Leonard, H., S. Cobb, and J. Downs, *Clinical and biological progress over 50 years in Rett syndrome*. Nat Rev Neurol, 2017. **13**(1): p. 37-51.
4. Allerton, L.A., V. Welch, and E. Emerson, *Health inequalities experienced by children and young people with intellectual disabilities: A review of literature from the United Kingdom*. Journal of Intellectual Disabilities, 2011. **15**(4): p. 269-278.
5. Young-Southward, G., et al., *Physical and mental health of young people with and without intellectual disabilities: cross-sectional analysis of a whole country population*. J Intellect Disabil Res, 2017. **61**(10): p. 984-993.
6. Bebbington, A., et al., *Hospitalisation rates for children with intellectual disability or autism born in Western Australia 1983-1999: a population-based cohort study*. BMJ open, 2013. **3**(2).
7. Davies, L. and C. Oliver, *The age related prevalence of aggression and self-injury in persons with an intellectual disability: a review*. Res Dev Disabil, 2013. **34**(2): p. 764-75.
8. Einfeld, S.L., L.A. Ellis, and E. Emerson, *Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review*. Journal of Intellectual & Developmental Disability, 2011. **36**(2): p. 137-143.
9. Hamm, B. and P. Mirenda, *Post-school quality of life for individuals with developmental disabilities who use AAC*. Augment Altern Commun, 2006. **22**(2): p. 134-47.
10. Albrecht, G. and P. Devlieger, *The disability paradox: high quality of life against all odds*. Soc Sci Med, 1999. **48**(8): p. 977-988.
11. Verdugo, M.A., et al., *Quality of life and its measurement: important principles and guidelines*. JIDR. Journal of Intellectual Disability Research, 2005. **49**(10): p. 707-717.
12. Neul, J.L., et al., *Rett Syndrome: Revised Diagnostic Criteria and Nomenclature*. Annals of Neurology, 2010. **68**(6): p. 944-950.
13. Davis, E., et al., *Exploring quality of life of children with cerebral palsy and intellectual disability: What are the important domains of life?* Child Care Health Dev, 2017. **43**(6): p. 854-860.
14. Epstein, A., et al., *Conceptualizing a quality of life framework for girls with Rett syndrome using qualitative methods*. Am J Med Genet A, 2016. **170A**: p. 645-653.
15. Epstein, A., et al., *Parent-observed thematic data on quality of life in children with autism spectrum disorder* Autism, 2019. **23**(1): p. 71-80.
16. Murphy, N., et al., *Qualitative analysis of parental observations on quality of life in Australian children with Down syndrome*. Journal of Developmental and Behavioral Pediatrics, 2017. **38**(2): p. 161-168.
17. Downs, J., et al., *Psychometric properties of the Quality of Life Inventory-Disability (QI-Disability) measure*. Qual Life Res, 2019. **28**(3): p. 783-794.
18. Imms, C., et al., *'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities*. Developmental Medicine & Child Neurology, 2016. **58**(1): p. 29-38.
19. Willis, C., et al., *Elements contributing to meaningful participation for children and youth with disabilities: a scoping review*. Disabil Rehabil, 2017. **39**(17): p. 1771-1784.
20. King, G., et al., *Predictors of the leisure and recreation participation of children with physical disabilities: a structural equation modeling analysis*. Children's Health Care, 2006. **35**(3): p. 209-234.



21. Bigby, C., S. Anderson, and N. Cameron, *Identifying conceptualizations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability: A scoping review*. J Appl Res Intellect Disabil, 2018. **31**(2): p. 165-180.
22. Shields, N., et al., *Is participation among children with intellectual disabilities in outside school activities similar to their typically developing peers? A systematic review*. Developmental Neurorehabilitation, 2014. **17**(1): p. 64-71.
23. Coster, W. and M.A. Khetani, *Measuring participation of children with disabilities: issues and challenges*. Disabil Rehabil, 2008. **30**(8): p. 639-48.
24. Kapsal, N.J., et al., *Effects of Physical Activity on the Physical and Psychosocial Health of Youth With Intellectual Disabilities: A Systematic Review and Meta-Analysis*. J Phys Act Health, 2019: p. 1-9.
25. Jensen, A. and L.O. Bonde, *The use of arts interventions for mental health and wellbeing in health settings*. Perspect Public Health, 2018. **138**(4): p. 209-214.
26. Jensen, A., *Mental health recovery and arts engagement*. Journal of Mental Health Training, Education and Practice, 2018. **13**(3): p. 157-166.
27. Fleming, E. and J. Whitaker, *The art of public health and the wisdom of play*, in *Play and playfulness for public health and wellbeing*, A. Tonkin and J. Whitaker, Editors. 2019, Taylor and Francis Group. p. 50-64.
28. Corbett, B.A., et al., *Changes in anxiety following a randomized control trial of a theatre-based intervention for youth with autism spectrum disorder*. Autism, 2017. **21**(3): p. 333-343.
29. Spiegel, J.B., et al., *Social transformation, collective health and community-based arts: 'Buen Vivir' and Ecuador's social circus programme*. Glob Public Health, 2019. **14**(6-7): p. 899-922.
30. Spiegel, J.B. and S.N. Parent, *Re-approaching community development through the arts: a 'critical mixed methods' study of social circus in Quebec*. Community Dev J, 2018. **53**(4): p. 600-617.
31. Loiselle, F., et al., *Social circus program (Cirque du Soleil) promoting social participation of young people living with physical disabilities in transition to adulthood: a qualitative pilot study*. Dev Neurorehabil, 2019. **22**(4): p. 250-259.
32. Farmer, H. and L. Maister, *Putting ourselves in another's skin: Using the plasticity of self-perception to enhance empathy and decrease prejudice*. Social Justice Research, 2017. **30**: p. 323-354.
33. Becker, E. and S. Dusing, *Participation is possible: A case report of integration into a community performing arts program*. Physiother Theory Pract, 2010. **26**(4): p. 275-80.
34. Sorzano, O.L., *Is social circus "The Other" of professional circus?* Performance Matters, 2018. **4**(1-2): p. 116-133.

