

Early Learning Group Experiences for Families of Children with Vision Loss

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Objectives of the Presentation:

- Share the findings of a pilot project completed with the supported of Monash University Occupational Therapy Students to re-establish early learning groups for families with children with vision loss. It included a literature review, project and evaluation.
- Facilitate discussion with attendees related to their experiences running similar groups and successful models for maintaining sustainability with current funding from NDIS.

Background

We know first-hand through our work that parents often share with us the feeling of isolation that can come in the early years when they feel like they are the only one raising a child with vision loss. We have ran groups in the past and have considered running more groups for families to attend for this reason. There are challenges in delivery this service due to low attendance, limited funding and resources to support them.

My Personal Experiences

Worked in the Early Intervention Program as an occupational therapist with Canadian National Institute for the Blind for 13 years.

When I started the “babies group” had been discontinued and the only opportunities for parents to meet was at our yearly Christmas party.

Parents voiced a need for group activities for them in the early years. Over the years planned play and activity groups but finally found the best success in running a monthly music therapy program with a consistent music therapist during the school year and a weekly program during a month of the school holidays at our office.

After trial and error we decided on a format of 15 mins. of announcements and discussion about a topic relevant to parenting a child with vision loss followed by 45 mins. Of music therapy. Families were welcome to stay after the group to talk to other families for additional time after the group.

Initially attendance was sporadic but after a few years we were consistently booked to capacity (8 families) and started a waiting list.

What helped to get this point was formal registration for each session, a nominal fee, a strict policy that if you were a no show without any communication with us, you were back on the waiting list and someone else would take your spot. Initially we phoned clients to remind them but this was not sustainable with our resources.

Besides the \$5 per session, no individual funding was used to run the group.

Survey of Parents

118 responses parents who have accessed Vision Australia services in the past two years Themes

Parents want:

- more groups including parent-child groups.
- to make connections, network with other like parents for peer support. Isolation (some of this is related to geography) is common. Parents don't know if there are other children with vision loss in their community.
- social activities for parents and carers.
- emotional support– could be peer or facilitated by staff.
- to meet people with lived experiences as someone with vision loss
- morning events and once a month play groups to meet parents and therapists, education and training around equipment, dressing skills, play and story time
- face to face play groups for sensory integration, socialization/social interaction and parental support at communal location,

QLD, NSW and VIC Groups

QLD, NSW and VIC have run Early Years Group Programs in the past 5 years with varying degrees of success.

NSW Groups

Not currently running groups.

Had an EI group up until 2018: At Enfield a monthly playgroup was organised for children aged 0-5 of all vision conditions. Each month the playgroup had a theme and the children's playroom would be decorated, music selected to match the theme, activities related to this theme would be organised and book keeping in line with the theme was read i.e. Christmas theme- Christmas decorations were made by the children and parents and then a scavenger hunt around the office where the children stuck the decorations on Christmas trees. We also had Santa and a Seeing Eye Dog as a reindeer!

We aimed to structure the session: Welcome, Free play, Structured fine and gross motor activities (crafts at the table and a moving activity), Story time

We generally had 2 VA staff members attend and sometimes a 3rd would be present. Our numbers started to dwindle though a number of factors but it was really difficult to gain attendance and generally saw the same 4-5 families attend. Playgroup numbers became most consistent when the session was structured.

Activities

NSW

Activities included:

- Paper plate craft (all kinds in line with the theme) Bingo (with the theme)
- Animal search (children had to find animals around the room and tick them off on their card) The animals had tactile aspects to assist children with no vision.
- Christmas decorations for the tree Colouring
- Play equipment was set up for gross motor
- The theme for the bear hunt had children going on a bear hunt through the room with different obstacles set up for children to go over and under, through and around.

Attendance

NSW

RSVP/registration

It was a group run when families attended on a voluntary basis.

We tried starting “RSVP before the day” so we could gauge numbers which did work for a time but then we just had less and less children. At the start of the year we asked families to nominate a preferred day and time and from this we scheduled playgroup to suit the majority. There were a few factors which contributed to less children.

We ran playgroup on a Thursday as this was the day most existing members could attend however new members who were interested may not have been free on this day.

Location

We saw the most dramatic drop in numbers when we moved offices to Parramatta. It took us a while to get started and organised for a new session

The location was also difficult for some families:

- Enfield was far for some families and then Parramatta was even further. We tried a session out of office in a central location however even then we only had 2 families.

Movement of families/family situations

The children who attended frequently either moved inter-state or started primary school. At the end we only had 2 children attend and that started being more 1 on 1 session then the children interacting (this was an issue both at Enfield and Parra)

Successes

NSW

Having a theme- children would dress up, the room would be decorated and all activities and story focussed on this theme. The day we had the fire truck come was probably the most successful. We had children 0-7 yrs at this event. The children were able to try turning on the hose and climb into the truck.

We attempted alternating VA staff members at the groups having physio, counsellor, OT present at different times to give parents variety and a chance to chat to all supports. This became difficult when staff numbers dropped or left and weren't replaced. In the end it was always an OT and counsellor.

Structure- Once we started structuring the playgroup it flowed much better. Children and parents knew what to expect

Challenges

NSW

Numbers- trying to get families to attend. We had a list of about 15-20 who would be sent the invite but we could never get any more than 7 (excluding the fire truck day where we had about 10) and on average would have 4-5 families attend throughout 2016 and about 2-3 families by the end of 2017.

We had all Sydney regions talking to families about playgroup and we had plenty of interest but getting people to the group was difficult.

QLD Groups

Gold Coast playgroup – run by Paeds OT, charged through NDIS, running presently but mainly 1-2 attendees. This has run for the past term or so.

Get Ready for Prep – ran annually for 2-3 years. We alternated between running a program over 2 days in January vs running a program in Nov/December, each week. Not running presently. We did charge families under Better Start group rate. Staff 1-2, depending on number of children attending 4-6. Attendance varied in January, which is why we then ran in Nov/Dec. OT/PT/SP used to have different fine motor, literacy, gross motor, social skills challenges and tasks for the children to complete during the day.

Children encouraged to problem solve areas that came up during the day organically (one child might say to another 'why do you have a stick (cane)?'. Very successful program as children attended with different levels of vision and different levels of advocacy skills, which provided peer to peer learning.

VIC Groups

Previously had parented play groups but have not been running it for the past 3 years until pilot project.

Have had story time at the Feelix library, NGV Experience, other literacy events. Some have been cancelled due to low registration.

Play day at local playgrounds – one off events

Why groups were discontinued

- Time
- Staff resources
- Change in staff and office space.
- Limited attendance
- Difficult to charge through NDIS

Funding

No program run so far have had a charge for parents to attend.

With block funding and Betterstart some funding was available for this.

The Project:

A project was completed in the Melbourne South East Region to develop Early Learning Groups for families with children with vision loss with the support of two Occupational Therapy student from Monash University. The project consisted of a literature review, a pilot group for six sessions at the Amiga Montessori site in Cranbourne West in Melbourne and evaluations with feedback from both parents and staff facilitators.

Summary of Literature Review:

Our literature review highlighted the need for children with and without vision loss to have early positive social experiences with their parents in a group situation. Please refer to the complete literature review for references that is attached to this presentation.

The Construction of the Group

A group format allows for a child with visual impairments to; Focus and maintains attention; Sit, listen and wait to take their turn; Follow directions and adjust to group expectations and Share knowledge and interests with peers

Playgroups increase the playfulness of a child aged 18 months to 5 years regardless of abilities and will foster language development

Parent involvement is key in the construction of groups

Increase in parents social support which can in turn optimise their parenting competence

Parents have an opportunity to bond with their child.

When a parent and child attend playgroup together, the child feels safe and secure and gains the confidence to explore the world, knowing that their loved one is there for them as a safe and reassuring base

Environment

Built/Physical: The Environment can act a barrier or facilitator to participation for children with visual impairments. Adaptation, reshaping and reconstructing the built and physical environment in terms of sufficient lighting, primary colours, minimising 'overstimulating' disturbances, overcrowding of objects and obstacles, ensuring consistency and familiarity

Social: The social environment can increase engagement and participation for children with visual impairment through having familiar people interacting and supporting them, in a safe and accepting environment, where they can have an enjoyable experience, free from judgement from other children and parents who do not have same lived experiences The social environment can be a crucial for parents and caregivers of the children with visual impairment to build on their social and support networks by giving them the opportunities to make connections with other people with similar lived experiences

Additionally, that parents who attended more regularly reported more benefits than parents who attended less often, particularly in relation to understanding their children's development, socialising with other parents, initiating activities and joining in with their children and modelling and applying what they learned from the supported playgroup at home. (AIFS, 2011).

Music Therapy in Groups

- Attentive behaviour is often higher than if they are participating in non-musical groups.
- Promote parent-child relationships as it allows the parent and child to do something pleasurable together.
- Promotes joint attention and physical contact between the parent and child
- Learn about dance by being close to another person and held while they move.
- Use of sound empowers the children as they are able to make use of their capabilities.
- Tools explored to tap with, tap on and shake.

Strategies to Support Inclusion and Development

The literature includes many successful strategies that assist helping children with vision loss to be better included in group and individual activities. Active participation of children promotes many areas of development and social participation.

The modelling of these strategies in a group setting can increase parents' confidence to use the strategies at home or in the community.

Format of the pilot project

- 6 sessions
- Maximum 8 families registered.
- Waitlist
- Routines
- 2 staff facilitators
- Off site

Challenges

Our pilot early learning groups presented challenges for both developing regular attendance and maintaining sustainability if we are to rely on NDIS funding for future groups.

Through careful consideration of our evaluation of these groups we have discussed improvements to address feasibility of running this as an ongoing group, the preferred format and optimal location.

We are also exploring other options that might be available to address the same objectives for these families if the group's format does not support this.

Changes Recommended

- Return back to our office space
- Once a month rather than every two weeks Fees
- Less structure
- Limit the group to 0-2 year olds

Different Ways to support parents

- Peer Facilitated Online Telephone
- Group programs without a specific focus on peer support

Discussion (10 minutes)

- What are you providing for parents to fill the need for peer connections?
- Are face to face group to hard and costly in the current environment?
- What support do parents need to participate?
- What are the roles of professional in supporting this? How can these opportunities be financially viable?

Ends