

# BEYOND LIMITS

How to run a mixed ability Youth Advisory Panel: key learnings from the Ombudsman for Children's Office




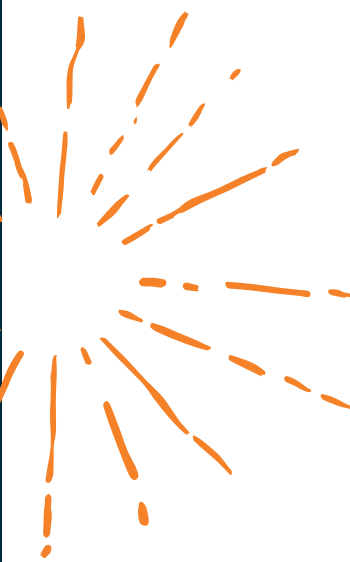
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# 1

## Summary

### Why Create a Beyond Limits Youth Advisory Panel

Beyond Limits is the Ombudsman for Children's Office (OCO) event for children and young people with disabilities and their families. It aims to show them the opportunities open to them, talk about the issues they want to talk about, and highlight inclusiveness. With Beyond Limits, we want to show how a fully inclusive event can be the rule and not the exception. Beyond Limits was first held in 2019 at Croke Park in Dublin, and again in 2022 at Knocknarea Arena, Atlantic Technological University Sligo and The Sports Arena, University of Limerick.

The Participation and Rights Education (P&RE) unit and the Communications unit in the OCO created the Beyond Limits Youth Advisory Panel (BLYAP) as part of its duty to fulfil its statutory obligations under s.7(2)(a) of the Ombudsman for Children Act, 2002:

*7(2)(a) The Ombudsman for Children shall establish structures to consult regularly with groups of children that he or she considers to be representative of children for the purposes of his or her functions under this section.*

The BLYAP was also a means to give effect to Article 12 of the United Nations Convention on the Rights of the Child: the child's views must be heard, considered and given due weight in accordance with their age and maturity in all matters that affect them.

The P&RE team aimed to work with children with and without disabilities to inform all aspects of the event. We wanted to give children the chance to offer their views, ideas, and preferences about creating an inclusive event and to bring their own messages and talents to the event. The BLYAP's role was identified as, but not limited to, the following:

- 1. Provide suggestions:** the BLYAP were free to share their ideas on what should be at the event, the content, the style and overall feel of the events.
- 2. Act as a sounding board:** the BLYAP sense checked suggestions and/or decisions made by the Communications Team and the internal OCO Beyond Limits Working Group, and made sure that they were making sound, child-friendly, inclusive and accessible decisions about the events.
- 3. Participate at the events:** the BLYAP were supported to take on roles at the events, with all of the participants getting involved. They delivered speeches, acted as co-hosts, facilitated interviews, sang and danced at the events.
- 4. Debrief after the event:** the BLYAP were encouraged to share their experiences of the events and make suggestions about how we could improve our work in the future.

# 2

## Benefits and Challenges

Working with a group of children with a range of physical and psychosocial disabilities has many advantages. Children and staff can learn from one another, increasing their knowledge and confidence, and staff can gain experience in working with children with different abilities. The BLYAP provided a unique opportunity to children and staff alike. It encouraged staff to be inclusive and accessible and it was empowering for the children to realise the power of their voices and messages. The BLYAP gave the OCO an insight into the needs/wants, opportunities/barriers open to children with different disabilities and various access needs, as well as increasing understanding of the views of children with varying and multiple disabilities.

There were also challenges associated with the project:

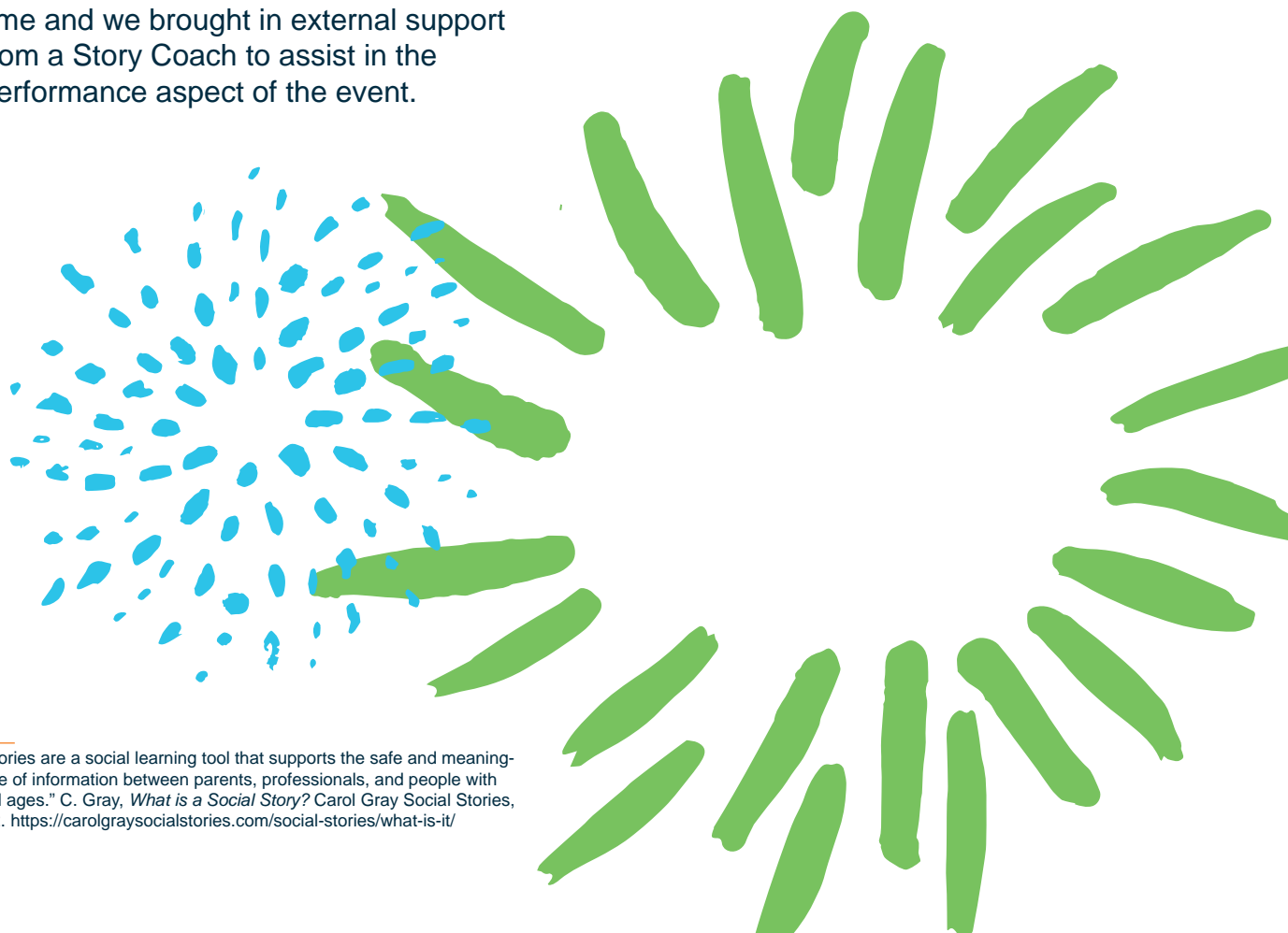
- 1. Active participation:** the inclusion and participation of all members of the group is essential to any well-functioning BLYAP. The P&RE team wanted to avoid creating material and content that would have the potential to exclude any child. The team provided a range of forms of self-expression, ensuring that the children participated in a way that was most meaningful to them, e.g. through talking, writing, drawing, videos, voice notes etc.
- 2. Facilitating the meetings:** it can be challenging to facilitate a group of children with different disabilities due to their competing and varied access needs. While the P&RE unit worked hard to include all participants in meetings, careful management of the group was essential so that all children were seen and felt that they were treated fairly.

**3. Managing expectations:** as with any group of children (or indeed adults), their expectations of what they could achieve or have influence over was addressed early and often. Staff checked in with the children regularly to ensure they understood the role of the BLYAP and what it could do. As such, clear roles and expectations were set out from the start through a child friendly Terms of Reference. The team also made a social story<sup>1</sup> to go along with the Terms of Reference.

**4. Managing participation at the events:** when the BLYAP decided that they wanted to participate in the events, the P&RE unit worked on building their capacity, increasing their confidence and gaining their trust. This took a lot of planning and staff time. Staff also needed to ensure there were no barriers to participation for the BLYAP on the event days. Staff put several plans in place and communicated frequently with the children and their parents about these. This process was resource intensive as it required a lot of staff time and we brought in external support from a Story Coach to assist in the performance aspect of the event.

**5. Attrition:** this is a risk with every group of children. The team expected that there would be some attrition. Fortunately, only one child withdrew before the first meeting due to conflicting commitments and no child left after this.

Staff tried to avoid the children wanting to drop out by ensuring that they were well supported and engaged. On-going communication between meetings and frequent updates were essential to maintaining engagement. The children also greatly benefitted from meeting face-to-face in our offices for the launch of the events. This gave them time to grow their friendships and want to see each other at subsequent meetings.



<sup>1</sup> "Social Stories are a social learning tool that supports the safe and meaningful exchange of information between parents, professionals, and people with autism of all ages." C. Gray, *What is a Social Story?* Carol Gray Social Stories, March 2022. <https://carolgraysocialstories.com/social-stories/what-is-it/>

# 3 Programme Administration Timeline 2022

Month	Action
January	<ul style="list-style-type: none"><li>Resources for Recruitment:<ul style="list-style-type: none"><li>Set out Terms of Reference for BLYAP alongside the Communications Team.</li><li>Produce a child-friendly version</li><li>Create a social story for potential participants summarising what BLYAP is</li><li>Create a short video for recruitment detailing what the BLYAP is and how to join</li></ul></li><li>Contact Disability Organisations to see if they have children they would like to put forward to the BLYAP</li><li>Contact interested children and their parents with consent and assent forms and social story detailing BLYAP</li><li>Send merchandise to interested children</li><li>Set up one to one meetings with each child and a parent to become familiar with needs and interests</li><li>Log all details returned on consent/assent forms in confidential database</li></ul>
February	<ul style="list-style-type: none"><li>Carry out all preliminary one to one meetings with children and parents taking note of any access requirements or particular interests</li><li>Request to each child for a picture and some information about themselves</li><li>Create an information booklet with the pictures and information and send it out to the children along with content for first meeting</li></ul>
March	<ul style="list-style-type: none"><li>First two group meetings take place, one at the start of March and one at the end of March</li><li>Material sent out for both meetings a week in advance</li></ul>

Month	Action
<b>April</b>	<ul style="list-style-type: none"> <li>• One to one meetings set up and carried out with a focus on what roles the participants would like to take on at the events</li> <li>• Third group meeting takes place (content sent a week before)</li> </ul>
<b>May</b>	<ul style="list-style-type: none"> <li>• Fourth group meeting takes place (content sent a week before)</li> <li>• One to one participant role meetings</li> </ul>
<b>June</b>	<ul style="list-style-type: none"> <li>• One to one participant role meetings</li> <li>• Fifth group meeting takes place (content sent a week before)</li> <li>• Date established for face-to-face get-together to launch the events in July</li> <li>• First meeting between staff and external contractor who will help participants with their performances</li> <li>• External contractor receives briefing on group dynamic and Terms of Reference of the group</li> <li>• Preference form for one or two events, dietary requirements and accommodation forms sent out</li> </ul>
<b>July</b>	<ul style="list-style-type: none"> <li>• Participant role meetings with P&amp;RE Team</li> <li>• Sixth group meeting (content sent a week before)</li> <li>• Logistics for get-together: travel, food, entertainment, access requirements, content</li> <li>• Get-together takes place in OCO offices.</li> </ul>
<b>August</b>	<ul style="list-style-type: none"> <li>• Participant role meetings with P&amp;RE team and external contractor</li> <li>• Group meeting 7 (content sent out a week before)</li> </ul>
<b>September</b>	<ul style="list-style-type: none"> <li>• Participant role meetings with P&amp;RE team and external contractor</li> <li>• Group meetings 8, 9 and 10</li> <li>• Social story sent out detailing accommodation and run through of event</li> </ul>
<b>October</b>	<ul style="list-style-type: none"> <li>• First event takes place</li> <li>• Debrief with children about event</li> <li>• Second event takes place</li> </ul>
<b>November</b>	<ul style="list-style-type: none"> <li>• Post-project focus group takes place</li> </ul>
<b>December</b>	<ul style="list-style-type: none"> <li>• Final goodbye face-to-face get-together in OCO</li> </ul>



## 4 Participant Profile

In February 2022, nine participants signed up to be part of the BLYAP. The geographical breakdown of participants was as follows: Offaly (1), Meath (2), Dublin (2), Cork (4). One child dropped out shortly after joining due to conflicting commitments and another child joined after the launch in July 2022.

There were six girls, two boys and one non-binary child. This was a group of children with a range of disabilities including Down Syndrome, autism, anxiety, ADHD and dyspraxia and one child with no disability but an interest in the issues.

## 5 Recruitment

Recruitment started in January 2022. Staff in the OCO contacted several disability organisations to ask them to put forward children they thought would be interested in the project. The Communications Team made a social media video explaining what the BLYAP was about.

Once the organisations had sent the names of the children interested, the Communications and the P&RE teams contacted the children and their parents. They sent them consent and assent forms, social stories to accompany the information on the assent and consent forms, draft Terms of Reference (ToR) with a child friendly version and social story explaining the ToR. The children also received OCO merchandise, including hats, pens, masks and water bottles.

# 6 Preliminary Individual Meetings

The Participation and Rights Education Unit had individual meetings with each child and, in some cases, their parent/s. Here, staff introduced themselves and asked the child to talk a little bit about their likes and dislikes. Staff then asked questions that were more specific, e.g., what way they like to receive information (picture, text, audio), if in text, what font size they like, and whether they need to receive information before meetings. Nearly all participants chose to receive the information before meetings. Some participants asked that the typeface be clear and that we use 12-point font at a minimum.

Others said they would prefer information through images/Picture Exchange Communications (PECs) and three participants used Lámh<sup>2</sup> as a communication tool.

The team told them a little bit about who and what the Youth Advisory Panel consisted of and what meetings would be like. Staff told them a little bit about the event so that they knew what they would be working toward.

# 7 Meeting Content

The content of the meetings needed to be child-centred, engaging, accessible, and to cater to all the children and encourage every child to participate. The meetings always began with a 'hello and how are you', followed by a dance break. After this, the facilitators had one or two questions for the group that sought guidance for the events. As Beyond Limits was an event managed by the Communications Unit, the P&RE facilitators relied on them to provide questions

they wanted answered week by week, e.g., activities, quiet room, speakers, and speakers' topics.

As the event got closer and as it became clear that the group wanted to play central performance roles, the design of the meetings focused more on their performances and less on informing the practicalities of Beyond Limits.

<sup>2</sup> With Lámh, speech is always used with signs and key words in a sentence are signed. Lámh currently has 586 signs - new signs for technology, sports and other general signs were added in 2019. Available at: <https://www.lamh.org/communication/about-1%C3%A1mh>

# 8 An Overview of Meeting Content

## Meeting One

- A simple guide to using Zoom
- Hello... my name is...
- What is Beyond Limits?
- A look at the 2019 video of Beyond Limits
- What is your favourite food?
- What things do you like that should be at Beyond Limits?
- Who would you like to speak at Beyond Limits?
- How do you feel after our first meeting?

## Meeting Two

- Hello how are you?
- What did you eat for breakfast?
- Why do we have a Beyond Limits BLYAP?
- What will make you feel safe and happy in this group?
- Updates on suggestions
- How do you feel?

## Meeting Three

- Hello, how are you?
- What is your favourite holiday?
- Venue unveiling: Sligo and Limerick
- Suggested speakers and performers for event
- Activities that have been booked
- What should we have in our quiet space?
- What jobs would you like to do?
- How do you feel after our third meeting?

## Meeting Four

- Hello, how are you?
- What is your favourite dance move?
- Let's look at the last Beyond Limits event.
- At Beyond Limits there will be... (what the Communications Team have already confirmed)
- Speakers and performers (what the Communications Team have already confirmed)
- Who were the 2019 speakers?
- What topics did they talk about?
- What topics do you think the speakers at the 2022 Beyond Limits event should speak about?
- Dance break
- How do you feel after our fourth meeting?



## Meeting Five

- Hello, how are you?
- Dance break
- Where is your happy place?
- What colour should the Beyond Limits t-shirts be?
- Dance break
- How will we tell people about Beyond Limits?
- If we make a video to tell people, who will be in the video?
- What will they say in the video?
- What will they do in the video?
- Update: Launch get-together
- How do you feel after our fifth meeting?

## Meeting Six

### Meeting Six

- Hello, how are you?
- Musical statues
- What will we do when you come to the office on the 23rd July?
- Video about what our office is like.
- Outline of what we plan on doing on the 23rd July.
- Do you have any questions about the get-together on the 23rd July?
- What do you think of the poster the Communications Team made for Beyond Limits?
- How do you feel after our sixth meeting?

## Meeting Seven

- Dance Break
- Hello, how are you?
- Welcome to Julien

- How the Beyond Limits Youth Advisory Panel has influenced the event so far
- What do you like to do for fun?
- What makes you feel proud?
- What is your role in Beyond Limits?
- How do you feel about your role in Beyond Limits?
- Dance Break
- How do you feel after our 7th meeting?

## Meeting Eight

- Dance Break
- Hello, how are you?
- We want to make things for people who come to Beyond Limits. What should we make?
- Talent Share. Do you want to share a talent with us? **Launch**

On July 23rd 2022, we had an in-person meeting in the Ombudsman for Children's Office to formally launch Beyond Limits 2022. We were joined by the children, OCO staff, one of our Beyond Limits hosts and a professional photographer.

## Launch day rundown

- Tour of building. Tea, coffee and snack bag
- Make a name badge
- Introductions
- Welcome message from Ombudsman for Children, Dr. Niall Muldoon
- Meditation
- Dance break
- Photo shoot with photographer
- Lunch
- BLYAP work on roles at events
- Feedback and wind down

# 9 Involvement in Decision Making

Throughout the meetings, staff ensured the children on the BLYAP had a say on important decisions about the events. Questions were threaded through the meetings and participants' influence and involvement developed over the nine months of their engagement. Based on the chronology of the meetings, we asked the children the following questions to inform important decisions about the events:

- *What things do you like that should be at Beyond Limits?*
- *Who would you like to speak at Beyond Limits?*
- *What should we have in our quiet space?*
- *What topics do you think the speakers at the 2022 Beyond Limits events should speak about?*
- *What colour should the Beyond Limits t-shirts be?*
- *What will we do when you come to the office on the 23rd July?*
- *What do you think of the poster the Communications Team made for Beyond Limits?*

It was of vital importance that staff showed respect for the children and their participation, both in the manner in which staff sought their views and how the OCO delivered on their suggestions. The BLYAP received the presentations for each meeting beforehand so that they had time to think about their responses. In the meetings, facilitators ensured that they kept their language clear and invited responses from all participants by whatever means they found most comfortable: verbally, in writing in the chat box or through Lámh, props or pointing.

The Communications and PR&E teams shared information between meetings about how the organisation of the event was progressing and which of the BLYAP's suggestions had been put in place. The P&RE team could then put this information into the presentation for the BLYAP meetings. The following inputs were given by the BLYAP and taken on board by the office:

- **What things do you like that should be at Beyond Limits?**  
Gymnastics, dancing, sport, silent disco, baking, quiet space, yoga
- **Who would you like to speak at Beyond Limits?**  
Mark Smith, Derek Ryan, Rod Stewart, the cast of Glee, Ellen Keane
- **What should we have in our quiet space?**  
Sensory toys, LED lights, blankets, darkness, cushions

- **What topics do you think the speakers at the 2022 Beyond Limits events should speak about?**  
Independence, inclusion, understanding, life ambitions, focus on ability
- **What colour should the Beyond Limits t-shirts be?**  
Pink and Purple
- **What do you think of the poster made by the Communications Team?**  
There is too much writing

The two Beyond Limits events were held two weeks apart. The first was in Atlantic Technical University, Sligo on 1st October 2022 and the second was in the University of Limerick Arena on 15th October 2022. Staff decided to run a debrief meeting with the BLYAP after the first event. From observation over the weekend of the first event, and on-the-spot feedback from BLYAP participants and their parents, staff were aware of the elements of the second event that needed to be changed to improve the experience for the BLYAP and which elements had worked well. The OCO team were conscious that the rehearsal on the evening before the first event was too long and that having to sit through a full run-through left the children and the parents tired and hungry. They were also aware that the children and their families needed more time by themselves.

At the debrief meeting the BLYAP members made valuable observations and advised staff on improvements that could be made for the next event. For example, one suggestion was to let the audience know that music would be played between each speaker and performance. This would give people with sensory or processing disabilities the chance to wear ear defenders, if needed, to avoid any sudden blast of music. Our BLYAP members also suggested that this announcement could be made at the same time as the other health and safety announcements, and this valuable change was implemented for the next event. Another suggestion to shorten the time for activities in between the speeches was also put in place for the second event.

In November, a few weeks after the final event, the P&RE team ran a post-event focus group with the children to reflect on the Beyond Limits events and to inform this report. As well as speaking about the emotional impact of the events, the children also continued to give ideas towards the improvement of future events. Their participative journey was therefore well-rounded: beginning with inputting into the logistics of the events, assuming a core role in the content, feeding back after the first event and finally engaging in the end-of-project focus group.

# 10 Role Preparation and Performances

Staff had at least two individual meetings with each BLYAP member to explore what, if anything, they wanted to do at the events. It is important to note that assuming a role in the events was voluntary for the children. Staff left it up to the children to decide a) if they were coming to one, both or neither of the events; b) if they wanted to assume a role at both, one or neither of the events; c) if they wanted an active role at the event(s), what role that would be. Some of the children were eager to come to and perform at both events, others felt that they would come to both events but perform at one, and others wanted to come to, and perform at, one event. This was a child-led process with the children telling us what they were comfortable with.

The BLYAP members decided on the following roles:

- Four children were to give speeches and two of those children also performed a song
- Three children were co-hosts
- One child interviewed a special guest
- One child was interviewed by the presenters

An external contractor specialising in story telling was hired to assist the children with the structure of their speeches. We had three to four individual meetings with each child to prepare these. The children were all keen to get across messages reflecting their experience of life. In a few instances, staff and the external contractor felt that a message a child wanted to share was too raw for them to speak of, that the child had not yet fully processed the story, and sharing it would put them in a vulnerable position. In these cases, staff worked with the child to determine what they were ready to share without affecting the core of their message.

The children had a variety of messages. One child spoke about the feeling of not being listened to, and that they felt mental health professionals had used their autism diagnosis to brush off any mental health concerns the child had. Another child spoke about the importance of sport being accessible to everyone. Being autistic in a mainstream school was the theme of another speech, as well as another child's journey to independence. It was evident that each child felt very passionately about their speech and their ownership of the words and story that stemmed from it.

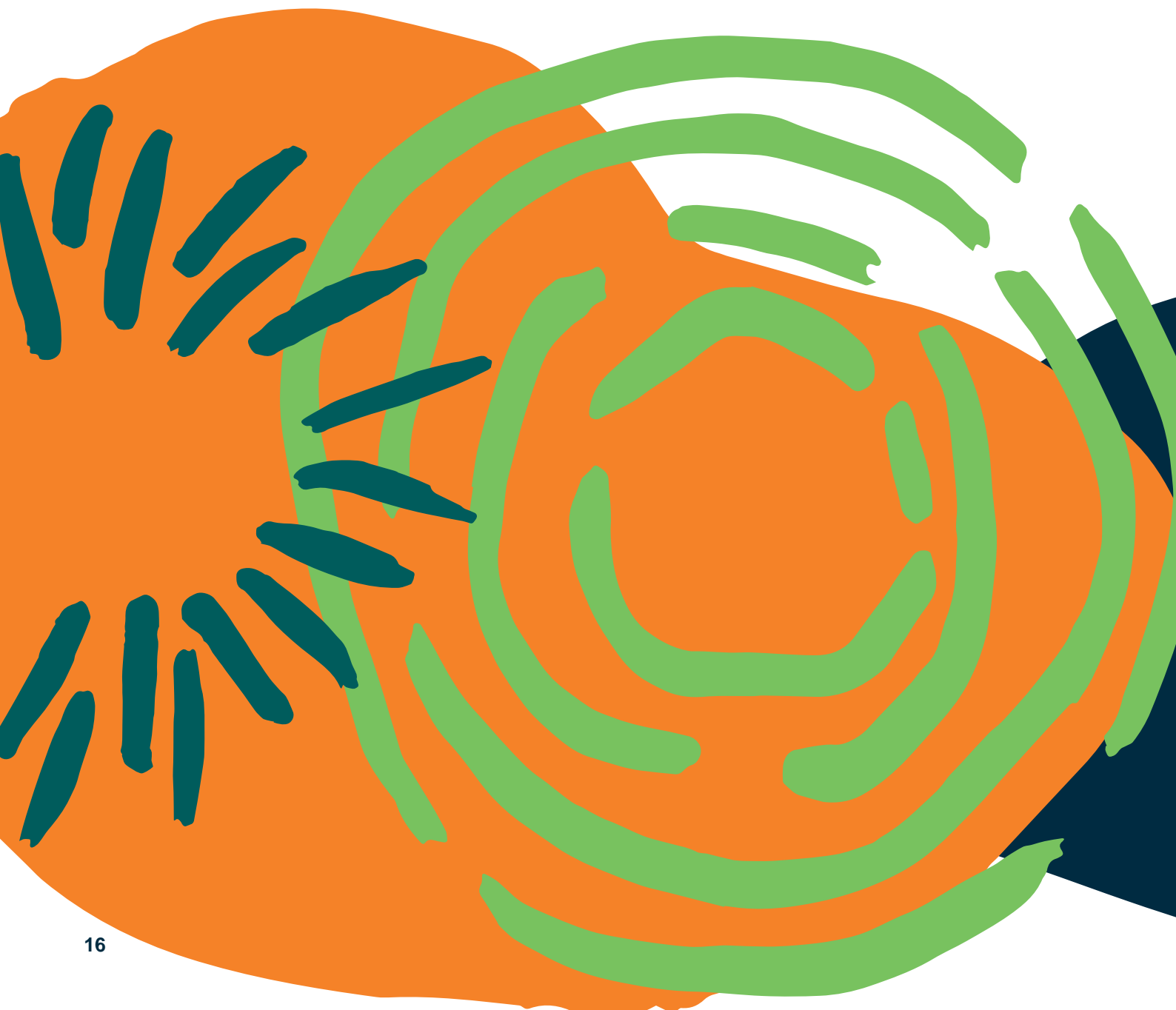
Staff met with the co-hosts several times before their performances. Together the team and the co-hosts came up with six or seven lines for them to say, including an introduction to the event, some information about themselves and an introduction to the next

speaker. Each meeting consisted of listening to each child, repeating and rehearsing their lines and giving the children a lot of praise. Staff tried as best they could to convey to the children what the event would entail and that there would be an audience present. Two of the children could do Lámh. One of these children used Lámh during their presentation and another followed their presentation with a song in Lámh.

On the day of the events, the co-hosts were particularly nervous and needed support before going on stage. The reality of a few hundred people looking at them hit them. However, they all got up on stage and performed exceptionally well.

It is important to emphasise that as well as being supported by the OCO to do their speeches and roles, the children's parents played a huge part in preparing them.

All of the children expressed how proud they were of themselves after performing and, as can be seen from the participants' feedback below, they realised that they had become advocates for other children in similar positions.





# 11

## Staffing the Project

As previously stated, the OCO has a statutory obligation to establish structures to consult regularly with groups of children and to give effect to Article 12 of the UNCRC. As such, the OCO was committed to supporting and resourcing the BLYAP.

Participation work takes time to deliver well and to avoid tokenism. It is necessary to build a rapport with children and understand their

needs so they feel comfortable expressing opinions. Added to that is the time it takes to prepare content for a mixed ability group to make sure that every child felt they could voice their view. The P&RE team were also aware that the children needed to feel supported taking on roles at the events and to do this the team met up with them on several occasions.

Below is an indication of the time dedicated by the P&RE team to the BLYAP.

	Initial Project Planning	1-2-1 Needs Analysis Meetings	Meeting Prep	Group Meetings	1-2-1 Role Meetings	Launch and Reunion Prep	Launch and Reunion	BL Events	Internal Working Group Meetings
<b>Staff</b>	1 staff member	2 staff members	1 staff member	2 staff meetings	2 staff meetings	1 staff member	4 staff members	2 staff members	2 staff members
<b>Time</b>	6 hours	4.5 hours	11 hours	11 hours	34 hours	4 hours	10 hours	24 hours	20 hours
<b>Total</b>	6 hours	9 h hours	22 hours	22 hours	68 hours	4 hours	40 hours	48 hours	40 hours

**Total hours:** 259 hours

**Total working days:** 37 days



# 12 Media Coverage

There was lots of media interest in Beyond Limits and the OCO partnered up with two local radio stations in Sligo and Limerick for both events. Members of the BLYAP appeared in the media from the time of the launch on 23rd July. The first piece, which appeared in the *Irish Examiner*, was a general overview of the events. The second, which appeared in the Parenting Column of the *Irish Examiner*, interviewed three BLYAP members about their involvement in the events.

BLYAP members were interviewed by Ocean FM and local radio in the Louth Meath area about their involvement in Beyond Limits.

RTÉ News covered the Sligo event, with three of the participants featuring on the *Six One News*.

Beyond Limits was also promoted extensively across the OCO's social media channels in the lead up to, during and after the event.

# 13 Children's Feedback on the BLYAP Experience

The impact of the project is most notable in two areas: how the BLYAP members felt about their involvement, and the effect of the participants' involvement on the structure of the event itself.

When asked how they felt before joining the first meeting, participants responded that they felt a mixture of emotions including happiness, nervousness and excitement. Some commented that the event itself was the attraction as it "sounded class". Another participant had attended the 2019 event so had a thorough understanding of what Beyond Limits was. This participant commented:

*"When I got invited to be part of it and part of the BLYAP, I was really excited and honoured to be part of such a wonderful event for people with disabilities."*

It was evident from some of the responses that previous experience of the event and/or having a sense of what the event had in store was a motivating factor for some of the participants.

*"When I first joined BLYAP I thought it was going to be a really fun event for people like me with special needs and disabilities and to get to talk about what it is like to have a special need and also a disability".*

Understandably, some of the BLYAP members were nervous and unsure about what to expect. From the outset, the OCO team were aware of this and practices to alleviate anxiety were put in place. The team met with each member of the panel before the first meeting and asked all participants to send in a picture of themselves and write a short introduction. This material was collated and sent to everyone on the panel. Feedback during the focus group showed that children appreciated this:





*“I really liked the way you got everybody to send in a picture and a little bit about themselves so you knew a little bit about people before you were in the meeting.”*

Though this helped the team understand the needs of the participants and to alleviate some of the children’s nervousness, the responses in the focus group revealed that it was only when they came together as a group at the first meeting that their anxieties truly dispersed.

*“When I first joined the Zoom call and had the very first meeting I was very happy to see that everyone was very nice and supportive to me.”*

Participants received the content of the meeting in a PowerPoint presentation a few days before every meeting. Every meeting had the same format. The BLYAP had requested dance breaks, and the P&RE team felt that a maximum of two questions was appropriate for every meeting. The P&RE team also felt that as the meetings were online, it was necessary to introduce two instances of physical movement per session. The format was as follows:

- hello, how are you?
- dance break
- participative questions
- dance break
- how do you feel?

The PowerPoints used PECS to allow concepts to be broken down into simple pictorial representations. In the focus group, the participants stated that even if they didn't always read the PowerPoints, they found it beneficial to receive them before the meeting.

*"Having the information before the meeting was really helpful because we had the information about what we were going to talk about."*

*"The PowerPoints were helpful. I liked knowing before the meeting what we were going to talk about."*

All participants stated that they felt happy in the meetings and liked giving their ideas. When asked what they would do if they were running the meetings, one participant suggested:

*"I would practice work out and exercise moves to get everybody all pumped up for our meetings and also I would also do meditation if we were all feeling anxious or worried about anything."*

Another put forward that opportunities to display talents should be introduced earlier on. Admittedly, the team only became aware of the breadth of the children's talents later on in the project, therefore making last minute additions to their performances, which may have caused unease to both the child and the event organisers.

*"It felt kinda cool that, you know, something that I said I wanted, happened. It was cool to see it, yeah. A little bit surreal."*

The primary motive for the formation of the BLYAP was children's participation. As such, it was imperative that the project avoided tokenism and the ideas and suggestions of the children were realised and evident in the planning and delivery of the events as far as possible. The children felt that they could see their suggestions and ideas at the events. When asked how this made them feel they responded:

*"It felt kinda cool that you know something that I said I wanted happened. It was cool to see it, yeah. A little bit surreal."*

*"It made me feel very happy [to see our ideas at the events]."*

When asked, the BLYAP members said that they felt supported in the run up to the events and their participation in them. This was because of good organisation, the provision of advice, numerous one to one meetings, and the offer of additional meetings if needed. The children felt that the help of an external contractor to structure and develop their speeches was also a benefit.

*"I think you did a really good job and I liked having [external contractor] there as well because like the first time you write your speech and he would give you pointers on how to make it more engaging for the audience."*

*"It was good to have the sessions with [external contractor] to prepare as a co-host. I became more confident with the practise sessions. He was fun and creative. Everyone was encouraging, too, asking us to do our best."*

When asked whether they felt supported during the events, the majority of the children responded that they did:

*“I did feel very much safe and supported and a lot cared for and also supported and given a lot of good advice for speaking out my speech at Beyond Limits.”*

One child pointed out that they felt:

*“A little more supported in Limerick [second event] just that we had the group meeting in the morning and we went off and did a few breathing exercises that was good. Sligo might have been a bit chaotic because the night before everyone was tired...”*

It was evidently important for the children to be in a calm space in the lead up to their performances. As this child pointed out, they appreciated the breathing exercises before the second event and the opportunity to have some quiet time. The P&RE team also observed the children independently using breathing exercises as a tool to quell any anxiety before their performances.

*“My best bit was when DR was singing, a little girl came over to me and asked me to dance with her. That just showed me how important days like Beyond Limits are because it wasn’t about disability, but it was about people just being themselves.”*

The P&RE staff concluded the focus group by asking the children about their highlights of the Beyond Limits experience. Two themes came through in their answers: friendship and advocacy. The group formed a very tight bond throughout the project. They found common ground in their shared experience of being a teenager in Ireland, and of being a teenager with a disability. The shared experience of the journey of being on the BLYAP, the strength it took to perform and their pride in themselves and each other afterwards bonded them together.

*“The best part of being on the BLYAP was making new friends. It was great to meet all of the people at the events. It was nice to celebrate together just being who we are. It was great to have the chance to speak on stage and to dance with the group.”*

The creation of a safe and enjoyable event for children with disabilities was important to the BLYAP.

*“My best bit was when DR was singing, a little girl came over to me and asked me to dance with her. That just showed me how important days like Beyond Limits are because it wasn’t about disability, but it was about people just being themselves.”*

Some children in the audience came to see the BLYAP participants as idols and this gave the participants a sense of self-worth and that they might be held up as positive examples and advocates for children with (and without) disabilities.

*“I remember in Limerick I went upstairs to do sports with my brother and sisters and on my way down a little girl wanted to take a picture with me and the little girl had the same name as me.”*

# 14 Parents' Feedback from Project

Parents of the BLYAP members played a vital role in the success of the project. The team were dependent on their involvement to support the children to attend meetings, practise performances and accompany them to the launch and the events. Staff therefore concluded that it would be valuable to get feedback from the parents as well as the children.

Parents were asked to consider three questions:

- 1) From your point of view, are there any changes you would make to the operation of the Beyond Limits Youth Advisory Panel (e.g. communication, support, meeting content, meeting delivery, timings etc., and get-togethers)?
- 2) Are there any changes you would make to the running of the Beyond Limits events?
- 3) What, if any, was the impact on your child of their involvement in the Beyond Limits Youth Advisory Panel and the Beyond Limits events?

Parents were overwhelmingly positive about the running of the BLYAP meetings. They commended the support that was offered to the children and how well-organised the project was.

*"The continuous support offered to [my child] was exceptional"*

*"I honestly thought the whole process was very well-thought out and ran very smoothly."*

Parents also appreciated the methods and activities employed by staff:

*"The child-centred, playful and patient approach made this an excellent experience for [my child]."*

They also pointed out that the in-person get-togethers were particularly meaningful for the children:

*"The in-person meetings brought a great atmosphere into the group as they got to know each other."*

One parent very helpfully suggested that staff think about the gap in between finishing up after the events and the Christmas reunion and farewell as their child really missed the meetings:

*"Maybe some thought could be put into how to wind down from the event afterward. I know [my child] missed the zooms when they finished."*

Parents also observed that their children's suggestions were taken on board by the office:

*"It was most excellent to see what the young people asked for come to life in the events."*

They reiterated their children's feedback that the rehearsal the night before the first event was too long and left them feeling exhausted:

*"The rehearsal in Sligo was very long after most people had been travelling."*

One parent pointed out that the cross-unit work demonstrated by the OCO was a good model of team-work for their child.

It is evident from the feedback that the children's participation in the BLYAP had an overwhelmingly positive impact. Three themes ran through the parent's responses in this regard: friendship, increased confidence and advocacy. Parents linked the children's developing friendship with their understanding of disability:

*"[My child] has grown in [their] understanding of disability through building friendships within the group."*

Another parent said:

*"[My child] has found a new group of friends who understand [them] and [they] can relate to. They have met up at [another participant's] house twice and will continue to meet up which has helped them feel connected which is what we all need."*

All of the parents who responded to the questions observed an increase in their child's confidence. One parent remarked that this

*"When a little girl also called [child's name] came up to her in Limerick and asked for a photo with her after listening to [child] she was so excited that she had helped another girl like herself."*

was particular to working with a group of other young people, which is an important skill:

*"[My child] has certainly grown in [their] confidence to work with a group of [their] peers."*

A number of parents emphasised the effect on their child's confidence in simply being themselves:

*"It is not easy being an autistic teenager in a mainstream school and Beyond Limits gave [them] a voice and the confidence to be [themselves]."*

*"His confidence and pride in himself increased so much. He told his extended family and friends and teachers at school who were all so supportive."*

The discovery that their voice and messages impacted other children meant a lot to the BLYAP members.

*"[They] really felt like [their] words matter and being honest about your experience is important."*

One parent reiterated the story her child had told:

*"When a little girl also called [child's name] came up to her in Limerick and asked for a photo with her after listening to [child] she was so excited that she had helped another girl like herself."*

Another said that their child has begun to question the structures around them because of their involvement in BLYAP:

*"[They have] begun to see/question/ and experience how people are treated differently."*

Realising the power of their voice was striking for the children:

*"[They] said [they] felt so empowered to have a voice and would love to do some more advocacy work in the future."*



# 15 Key Lessons and Learnings

As a result of the feedback from the Beyond Limits Youth Advisory Panel and the success of the events, the P&RE team were satisfied that the project had gone well. On reflection, the team saw the following actions as being important factors in the success of the project:

- 1) All communication needs to be inclusive from the start through use of voice notes, Lámh, social stories, PECs etc.
- 2) Have one to one meetings with the children before the first group meeting to establish needs, likes, dislikes and to become familiar with the facilitator/s.
- 3) Design and deliver meetings with children's needs in mind, e.g., send out information a few days in advance of meetings and allow for movement breaks during meetings.
- 4) Clear feedback needs to be given to the panel about any views they express or suggestions and ideas they have for the events.
- 5) The online format is good to cater for geographical spread. However, holding one or two in-person get-togethers as well as the events, really allows the children to create a bond and feel more comfortable with each other and with the organisation.
- 6) Consistent communication with both parents and children in the lead up to the events is vital to calming nerves and anxieties.
- 7) Children need support to carry out performances. The extra one to one meetings were effective in doing this.
- 8) Debrief sessions after each event were effective ways of learning about what works and what doesn't.
- 9) The children needed some closure after the intensity of the project. An end-of-project party or other form of celebration and conclusion helps children to wind down.

# 16 Links to View Events

1st October 2022 Knocknarea Arena, ATU, Sligo

<https://www.youtube.com/watch?v=7IDb626-XBE>

15th October University of Limerick

<https://www.youtube.com/watch?v=vDB3yC0tT7w>



# 17 Appendices

- **Appendix I:** Recruitment Social Story (What is Beyond Limits?)
- **Appendix II:** Beyond Limits Youth Advisory Panel Consent and Assent Form
- **Appendix III:** **Assent Social Story**
- **Appendix IV:** Terms of Reference
- **Appendix V:** Terms of Reference Social Story
- **Appendix VI:** Example Meeting (PowerPoint)
- **Appendix VII:** Social Media Posts

# Appendix I: Recruitment Social Story



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The Ombudsman for Children's Office or the OCO protects children's rights.

## BEYOND LIMITS<sup>19</sup>

Empowering young people with disabilities

The OCO holds an event called Beyond Limits.



Beyond Limits is an event for children with disabilities.



This year we are having two events in October for children with disabilities and their families.

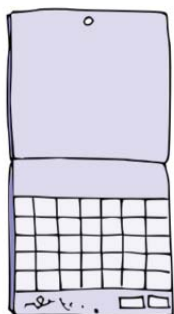


It is really important that we know how children with disabilities would like these events to be run.



That is why we are asking you to join our Beyond Limits Youth Advisory Panel or BLYAP.

Do you want to join?



If you want to join,  
you will come to  
one meeting each  
month.



The  
meeting  
will be  
about 45  
minutes  
long.



The  
meeting  
will be on  
Zoom.



Your mum or dad  
can help you.



If you would like to join the  
Beyond Limits BLYAP email  
[communications@oco.ie](mailto:communications@oco.ie)

# Appendix II: Youth Advisory Panel Consent and Assent



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**BEYOND  
LIMITS<sup>19</sup>**  
Empowering young people with disabilities

## Beyond Limits Youth Advisory Panel (BLYAP) Information

Beyond Limits is an event for children with disabilities. At Beyond Limits, children can talk about issues that are important to them and hear about other peoples' experiences about living with a disability.

This year we are having two events in October for children with disabilities and their families.

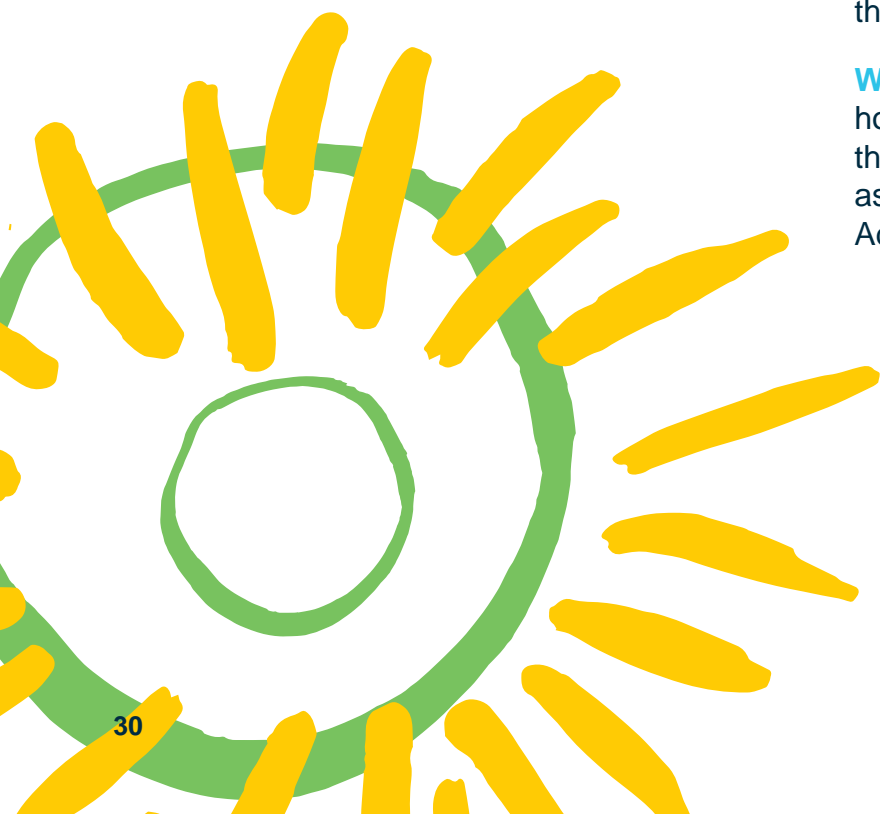
**Meetings:** One per month.

**How long for:** 45 minutes.

**When:** After school or on a Saturday – to be decided by the children in the BLYAP.

**What:** The BLYAP will help staff in the Ombudsman for Children's Office to organise two events for children with disabilities. This could be helping us plan entertainment, speakers and exhibitors for the events.

**Why:** It is really important that we know how children with disabilities would like these events to be run. That is why we are asking you to join our Beyond Limits Youth Advisory Panel or BLYAP.



# Parent/Guardian Consent Form

Name of Child:.....

Child's Phone number: .....

Child's email address: .....

Name of Parent/Guardian:.....

Parent/Guardian Phone number:.....

Parent/Guardian email address: .....

Does your child have any addition or medical needs/allergies?

.....  
.....

Consent to take part in the Beyond Limits BLYAP

*Please tick the box if you consent:*

**I agree** that my child can take part in the OCO's Beyond Limits Youth Advisory panel and share their opinion and experiences as part of the Beyond Limits Youth Advisory Panel.

**I agree** that the OCO can communicate with me/my child via WhatsApp and email to arrange meetings and provide more information on Beyond Limits in the lead up to the events

Signature of Parent/Guardian:.....

Date:.....

If you have any questions, please email XXX: XXXXX@oco.ie



## Child Assent Form

If you want to join the Beyond Limits Youth Advisory Panel, you should read the information book and then sign this page.

### Assent to take part in the Beyond Limits BLYAP



#### Things to think about...

I do not have to be a part of the Beyond Limits Youth Advisory Panel if I don't want to.

If I join the Beyond Limits Youth Advisory Panel, I will be asked to share my opinions and experiences.

If I join the Beyond Limits Youth Advisory Panel, I will be asked about my ideas for an event for children with disabilities.

If I am a part of the Beyond Limits Youth Advisory Panel, I will work with other children and OCO staff.

The OCO will listen to my views but they may not be able to do everything I want for Beyond Limits.

Name: .....

Age: .....

I agree that the OCO can communicate with me/ my parent/guardian via WhatsApp and email to arrange meetings and provide more information on Beyond Limits in the lead up to the events.

I have read and understood the information and I want to join the Beyond Limits BLYAP. (Tick one)

YES  NO

Signature of child: .....

If you have any questions, please email: XXXX@oco.ie



# Appendix III: Assent Social Story

## BEYOND LIMITS<sup>19</sup>

Empowering young people with disabilities

Welcome to the Youth Advisory  
Panel for Beyond Limits 2022.



We want to make sure that you want  
to be on the Youth Advisory Panel.

I have read and understood the information and I  
want to join the Beyond Limits YAP. (Tick one)

YES



NO



We want you to tell us if you want to be  
a part of the Youth Advisory Panel on the  
Assent Form we sent you.



We want  
you to tell  
us what  
Beyond  
Limits  
should be  
like.

We want you to  
meet us for 45  
minutes every  
month in a Zoom  
call with other  
young people.



If you think you  
want to tell us what  
Beyond Limits  
should be like and  
meet other children,  
you should tick yes.

If you do not want to  
tell us what Beyond  
Limits should be  
like and you do not  
want to meet other  
children, you should  
tick no.



The most  
important thing  
for us is that you  
are happy.



# Appendix IV: Terms of Reference



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## Beyond Limits Youth Advisory Panel

### The Why, Who, What, When, Where & How's!

#### Why?

The BLYAP will help staff from the Ombudsman for Children's Office (OCO) create and plan our Beyond Limits events in 2022.

#### Who?

Members of the Beyond Limits BLYAP will be between 13 and 17 years old and live in Ireland. The BLYAP will include children from different backgrounds and with different abilities who work with OCO staff.

#### What?

The Beyond Limits BLYAP will give us advice on our Beyond Limits events in 2022. We would like them to share their thoughts with us on the experiences, preferences and needs of children with a range of disabilities. The BLYAP will:

- 1. Make suggestions:** the BLYAP can freely share their ideas on what should be at the event.
- 2. Check that the OCO is getting things right:** the BLYAP will check the decisions made by the OCO to make sure that we are making choices that make sure that the events are child-friendly, inclusive and accessible.

**3. Participate at the events:** the BLYAP will be able to take on roles at the event, if they want to. The BLYAP do not have to do anything on the day of the events if they do not want to.

**4. Give us feedback after the event:** the BLYAP will share their experiences of the events and taking part in the BLYAP and make suggestions about how we can improve our work in the future.

#### When and Where?

The BLYAP meetings will be in the evenings or on a Saturday, if everyone in the group agrees. The BLYAP will meet once a month for 45 minutes on Zoom. We also hope to have an in person meeting.

#### How?

The BLYAP meetings will be facilitated and chaired by the Participation & Rights Education Unit (Aoife McNamara, Carmel Corrigan or Clare Sheppard). What we will discuss and the PowerPoints will be sent to the BLYAP before the meetings, so that everyone has time to prepare and think about what they want to say. A short note of each meeting will be sent to the BLYAP afterwards.

# Appendix V: Terms of Reference Social Story



**BEYOND LIMITS<sup>19</sup>**  
Empowering young people with disabilities

## Why?

The BLYAP will help staff from the Ombudsman for Children's Office (OCO) create and plan our Beyond Limits events in 2022.



## Who?

Members of the Beyond Limits BLYAP will be between 13 and 17 years old and live in Ireland. The BLYAP members will be from different backgrounds and with different abilities who work with OCO staff.



**The BLYAP will make suggestions:** the BLYAP can freely share their ideas on what and who should be at the event.

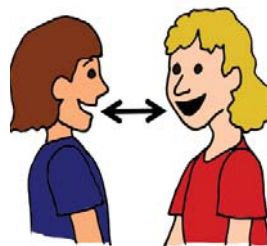


## Check that the OCO is getting things right:

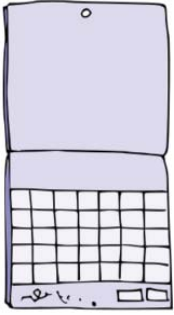
the BLYAP will check the decisions made by the OCO to make sure that we are making choices that make sure that the events are child-friendly, inclusive and accessible.



**Participate at the events:** the BLYAP can take on roles at the events, but only if they want to.



Give us feedback after the event: the BLYAP will share their experiences after the events and make suggestions about how we can improve our work in the future.



### When and Where?

The BLYAP meetings will be in the evenings or on a Saturday, if everyone in the group agrees. The BLYAP will meet once a month.



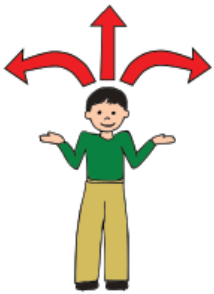
The meeting will be about 45 minutes long.



The meeting will be on Zoom. We also hope to have an in person meeting.



Your mum or dad can help you. You can also tell us if you need help.



The information you will need for the meetings will be sent to you before the meeting, so that everyone has time to think about what they want to say and the choices they want to make.


# Appendix VI: Example Meeting (PowerPoint)

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## BEYOND LIMITS<sup>22</sup>

Empowering young people with disabilities

Meeting Two:  
Youth Advisory Panel

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## Hello! How are you?



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## What did you eat for breakfast?



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## Why do we have a Beyond Limits Youth Advisory Panel?



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## What will make you feel happy and safe in this group?



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## News





We have contacted the sign language choir



We are planning a silent disco



We have contacted Joanne O'Riordan, Mark Smith & Sinead Burke



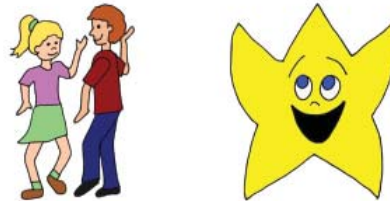
Ellen Keane is going to be the presenter



Gymnastics Ireland would love to take part



Dancing with the Stars want to get involved



There will be quiet spaces in both venues



How do you feel after our second meeting?



Thank you!

# Appendix VII: Social Media Posts

**Ombudsman for Children** @OCO\_ireland · Aug 3, 2022



We were thrilled to have @PaddySmyth & members of our Youth Advisory Panel at the launch of #BeyondLimits, the OCO's free event for children with disabilities & their families coming to Sligo on Oct 1st & Limerick on the 15th.

**Ombudsman for Children** @OCO\_ireland · Aug 17, 2022



We have an incredible line-up for Beyond Limits in Sligo and Limerick this October 🙌

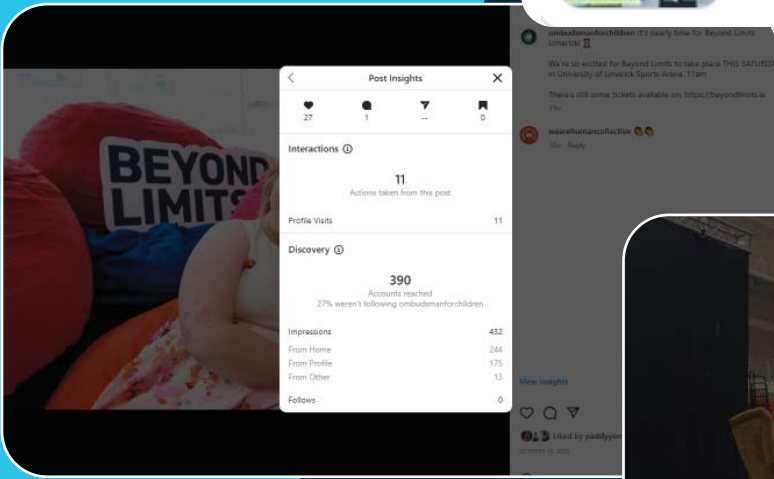
We'll be joined by @James22034777 who'll be telling us all about his adventures on Ireland's public transport ...

**Ombudsman for Children** @OCO\_ireland · Sep 28, 2022



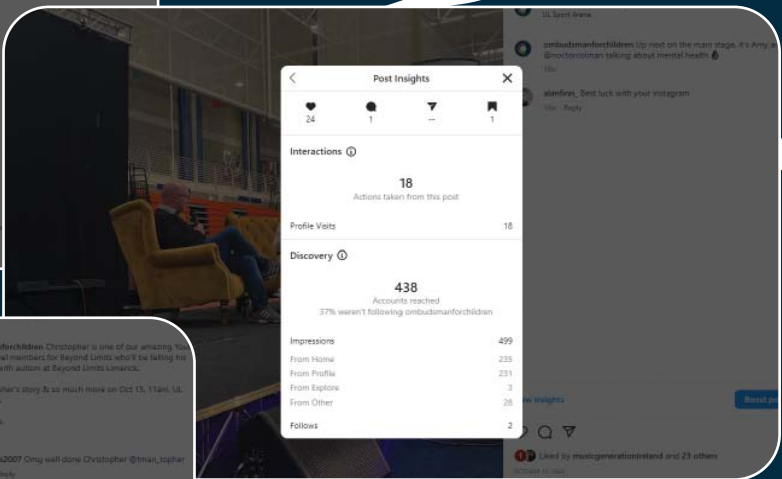
It's nearly time for Beyond Limits 2022 Sligo! ⏰

We're so excited for Beyond Limits to take place THIS SATURDAY in Sligo, Knocknarea Arena.



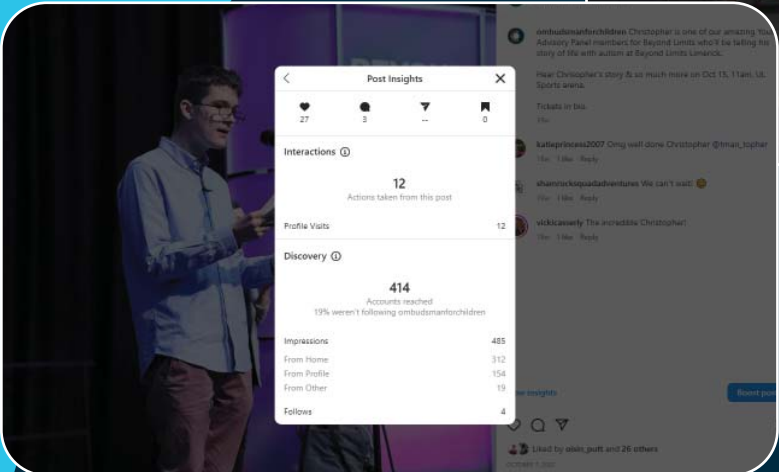
**Post Insights**

Interactions	11
Profile Visits	11
Discovery	390
Accounts reached	27%
Impressions	432
From Home	244
From Profile	175
From Other	13
Follows	0



**Post Insights**

Interactions	18
Profile Visits	18
Discovery	438
Accounts reached	37%
Impressions	499
From Home	235
From Profile	231
From Explore	2
From Other	28
Follows	2



**Post Insights**

Interactions	12
Profile Visits	12
Discovery	414
Accounts reached	13%
Impressions	485
From Home	312
From Profile	154
From Other	19
Follows	4



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X: @OCO\_Ireland