



INCLUSION IRELAND

National Association for People with an Intellectual Disability

**COVID-19 and the impact of
the Closure of day services on
People with intellectual
disabilities**

July 2020

**This document is written in font 12 Verdana in line with Inclusion
Ireland plain English guidelines**



Day Services and Covid 19

Report summary



In June we did a survey on the internet when day centres were closed because of Covid 19.

We asked people with disabilities and their families what support they got from their service.



Half of the people said that they had little or no contact or support from Day Services during the lockdown.



Some people just got a few phone calls or text messages.

Some services sent out activity packs and had meetings by Zoom.



Some people liked using the internet to learn things.

They liked to meet staff and friends on Zoom



Most people found it hard to use computers or smartphones without support.



Some people didn't have computers or smartphones or internet connections.



Loneliness and worry were big issues for many people with disabilities during the lockdown.

Some people also felt angry and didn't understand what was happening.



2 out of every 10 people said they felt happy to be at home.



People missed having a plan for how they would spend their day.

The most common activity at home was watching the TV and listening to music.



Some people also did exercises like dancing or walking.

Some people did cooking and arts and crafts.



People said the most important support was talking to staff.

They also really wanted to meet their friends and spend some time in the day centre.



Most people wanted the day service to open up again.



But half of the people were still worried that Covid 19 might spread in the Day service.



They thought it might be hard for some people to keep their distance from staff and friends.



Everyone wanted clear information from the day service.

They wanted to be asked what they needed.



They wanted to know

- What support they would get,
- When they would get it
- How the centre would be made safe.

They wanted a plan

About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights-based advocacy organisation that works to promote the rights of people with an intellectual disability.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights.

Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy and we use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to guide our work.

Introduction

In mid-March Disability day services closed to people with intellectual disabilities with a small number of exceptions. In May and early June, Inclusion Ireland surveyed the people who use these services and their families on the impact the closure of service has had on them and the supports they have received in this time. In total, 291 family members answered our survey and 55 people with intellectual disabilities responded to an easy-to-read version of our survey giving a total response of 346.

Peoples engagement with their service over the Covid period has been variable with some people reporting regular contact, daily online activities, and some face to face support while more than half of respondents have had very little meaningful contact at all.

The closure of day services impacting on the mental health of people cannot be underestimated. A significant number of respondents reported increased loneliness, increased anxiety, and increased challenging behaviour or anger. At the same time more that 20% of people reported being happier during the lock down.

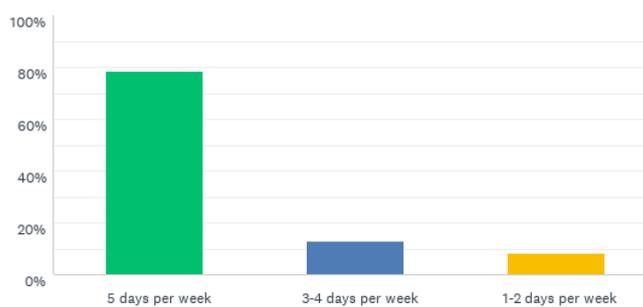
As services reopen and start to support people with intellectual disabilities in a 'different or remote' manner the needs of people with high support needs and complex disabilities must be considered carefully. This group of people tell us they cannot access virtual technology even with one on one family support to do so.

Day service attendee profile

Of the people who completed the online surveys 85% were living in their family home. The other 13% of the people were living in a group home in the community, living independently and 2% people were living in a large institution.

79% of respondents normally attended day services for 5 days per week, 13% were attending for 3-4 days per week and 8% attending for 1 or 2 days per week.

Q2 Before Covid 19, how many days a week did they normally go to their day service



38% of respondents said that their family member needed 1:1 support to participate in their day service; 31% needed a moderate level of support; 17% needed a low level of support and a further 14% were relatively independent.

Q3 What level of support do they need to participate in the day service?



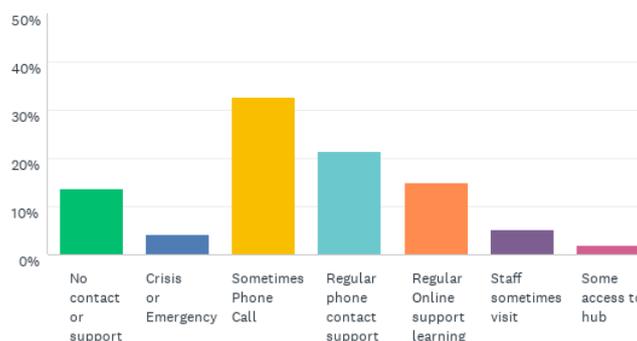
The lockdown experiences

Contact between services and the people they support has been variable with 54% of respondents indicated that they had little or no contact or support from Day Services during the lockdown. The 54% breaks down to 15% had no contact, 5% indicated that they were told they could get support in the event of an emergency or crisis and 34% indicated that they occasionally got a call to ask how they were getting on.

On the other hand, 22% of people had regular contact and support from staff by phone, a further 16% had regular online support for activities and learning. 6% had occasional home visits from staff and 2% had direct access to their day centre.

One third of people with intellectual disabilities said they have had little or no contact from their service.

Q7 What contact or support are they getting from the day service since it closed?



People told us

“An odd text message, nothing else for 10 weeks”

“Hugely disappointed with the service and HSE. Absolutely forgotten about with very little to offer either support to the family who care for them 24/7”

“None - just a box ticking phone call and our vulnerable relative was left to their devices.”

“Send out a pack once a week - magazine, activities etc and a call”

“Staff member calls 2 times a week to go for a walk in the locale and to collect DA (disability allowance) from Post Office”

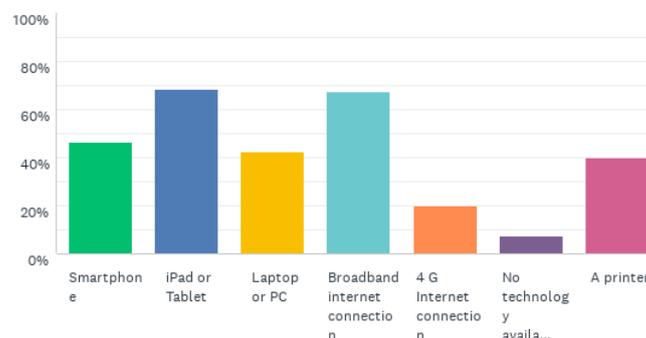
As contacts between services and people who attend the service have been mostly remote in manner due to public health guidance, we asked people about their access to technology and their capacity to use it.

In terms of equipment that was available for use at home, an iPad or tablet was available in 68.5% of homes, a smartphone in 48.5% and a laptop or PC in 42.6% of homes. 7% of people had no access to computer equipment at home.

67.5% of homes had access to a broadband connection and a further 19% had access through 4G only. This means 12% of respondents indicated that they had no internet access at home. This is likely to be an underestimate as this survey was hosted online.

We also included a question about access to a printer, to cover the possibility that Day services may want to email resources for printing at home. Only 40% of respondents said that they had access to a printer at home.

Q4 Does your family member have access to any of the following in their home? (tick any options that apply)



In the comment section of the question on the ability to use technology, 56 respondents (19%) stated that the person they support could not use any of the technology options identified due to the level of their disability. A further 6 people (2%) indicated that they could only access any computer-based technology with substantial ongoing support. So, 21% of the people supported could not use basic information technology equipment and software, even when it is available.

In terms of the technology that people with disabilities had access to and could use with or without support, the most accessible tool identified was an iPad or tablet – 168 (60%). Only 109 people (38%) had access to and

could use a smartphone. People with disabilities themselves, noted greater access to smartphones and the internet.

In terms of communications, only 33% of people were capable of using zoom or skype; 30% could use WhatsApp; Email (13%) and Facebook (16%). Just over half of people with intellectual disabilities said they needed support to use technology.

People told us

“There is online activities, but unsuitable to ‘Pats’¹ level of needs”

“It took them 7 weeks to do work on zoom. They sent links to my daughter. I asked for hard copies to be sent. She gets 2hours a week!”

“As my child is non-verbal and severely autistic with complex medical needs, he is unable to participate or understand online learning”

“WhatsApp photos of the clients/friends in the day services and the photos of staff saying hello and they are missed”

“Weekly phone call from class teacher Weekly class zoom meeting Weekly post”

People with intellectual disabilities have had to adjust to life mainly in the home during lockdown. Family members said the main activity was watching TV (72%) and Listening to or playing music (60%) and 71% of people with a disability reported greater participation in exercising.

In commenting on this section, a few respondents identified excellent support from services (online learning and online Physio and SLT) while more expressed the frustration of little or no contact with services compounded by the significant additional stress of full-time caring without external stimulation or activities. Virtual contact was also identified as a support that did not work at all for those who are non-verbal or with high support needs.

The impact on people’s lives

The Covid 19 crisis, lockdown and closure of day services is clearly having a significant impact on the mood and feelings of the people who are being

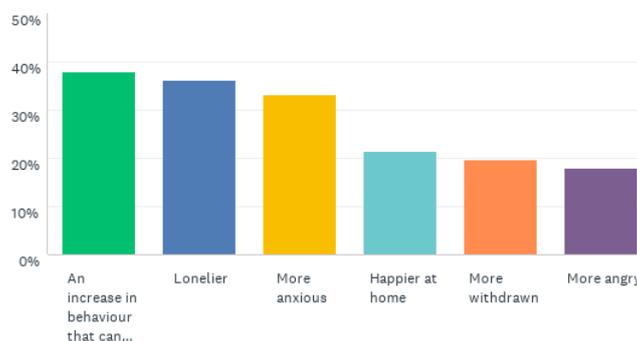
¹ Name made up to protect identity

supported by disability services. In terms of mental wellbeing, 38% of respondents indicated an increase in behaviours of concern, 36% indicated an increase in loneliness and 33% an increase in anxiety for their family member. There is also increases in anger and people feeling withdrawn. For people with intellectual disability, loneliness was a significant issue for 56% of respondents.

However, 22% indicated that their family member is actually happier at home, and in some instances, this was giving rise to concerns that the return to day service and new routines might be quite challenging. People with intellectual disabilities reported slightly higher levels of happiness at home at 30%.

Other respondents indicated significant concerns about regression in skills during this period.

Q8 Have you noticed any significant change in your family member's mood or feelings since the day service closed (tick any that apply)



People told us

"Happy at first but now anxious at times and not sleeping at all some nights."

"Much more withdrawn, very worrying. All gains in confidence and independence to date unravelling as we speak."

"Happy at home but also is missing social aspect of meeting staff and friends"

"Very bored and unstimulated"

"Definitely very happy at home but desperately missing his friends and teachers"

“It depends on the day. Some days can be brutal, but others are ok.”

“Biggest change is sleeping routine. He stays up until 2 or 3 am and it’s hard to get him up in the morning as he has nowhere to go”

“Suffering from stomach problems in last month ... doctor suspects anxiety from effects of missing friends & normal day services”

“Self-harm, not sleeping, lashing out”

“Teary and patches of depression from an otherwise cheerful and happy woman.”

“Lonely till we got on zoom and he is happy now but misses his job on Thursdays”

The supports people want

We asked people to rank a list of additional supports to address their current concerns, the highest ranking answer was “phone contact with staff for advice and support” closely followed by “some access to their hub or day centre for activities and support”. Online support is ranked 3rd with only 14 people indicating this as a first preference.

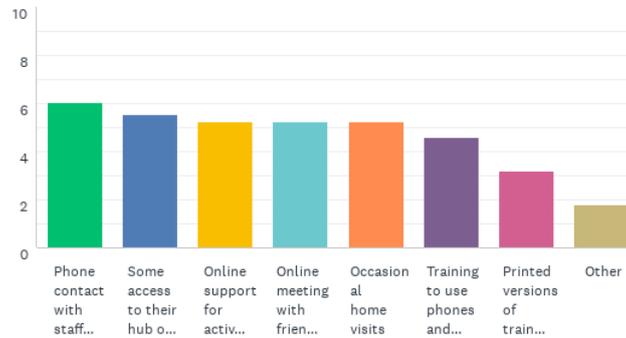
When you look at first preferences the top three were as follows: 35% chose access to the day centre, 29% chose phone contact with staff, and 16% chose occasional home visits. There is a clear preference amongst people who are providing support at home for direct contact with staff and for advice and support, rather than for virtual online contact.

It has already been stated earlier that face to face support is the only form of day service that will work for people with complex disabilities.

Respondents were asked to identify one priority change in the way day services provide support while the current restrictions are in place.

For 27% of respondents, the most important priority was some level of actual physical presence and communication between their family member and their friends or support staff. This could be accomplished by socially distanced home visits, walks or other outdoor activities.

Q9 What additional supports do you think would be most useful (rank in order of importance)



"We have no support; our daughter is fed up being at home and needs to see other people and do something different."

"Personal contact with staff & peers This cannot be replaced with on-line sessions ... My son started Zoom sessions last week & is rapidly losing interest already ..."

17% of respondents hoped that it might be possible to accomplish this by having some time, however limited, in the hub or day centre.

"My daughter needs to get back to her day service, she doesn't enjoy online, and she is spending too much time alone and misses her friends and her routine"

"I don't think anything apart from resumption of services will help. My son cannot understand distance learning"

By contrast, 14% of respondents felt that increased virtual contact by phone or online was a priority change.

"More contact with the staff for the service user. One of my girls had none for a few weeks. She felt so isolated. Since contact has resumed by phone, she has another person to chat to and more news to report"

"To have daily interaction with peers even if for just an hour or half and to have classes online, but this all takes time and we appreciate that but social interactions and skills will be lost"

"A weekly phone call from staff. My daughter received 2 calls since 12 March and her absolute joy and happiness was incredible"

"A structured daily plan e.g. using Zoom calls, with the opportunity for small meetings outside the home a couple of times a week."

19% of respondents indicated their priority need for brief respite and/or home support.

"As carers we are now working 24/7. We have no respite whatsoever. No family support due to elderly grandparents, our levels of exhaustion are extreme at this stage. But we are the forgotten."

"I would just love some support to let me even have a five-minute break"

"It would be great just to have a break from each other as there is not a lot we can do together. We do have a walk every day but that is not enough for him he just loves his day-care"

For 12% of respondents better communication from the service and a clear plan and timeframe for resumption was the priority change identified.

"More communication on how they are going to phase them back into the centre, to know they are working on a plan, and that even a few hours a couple of days a week begins very soon"

"I need help to explain to him about the virus and the reason for the closure and re-assurance that it will open but be different"

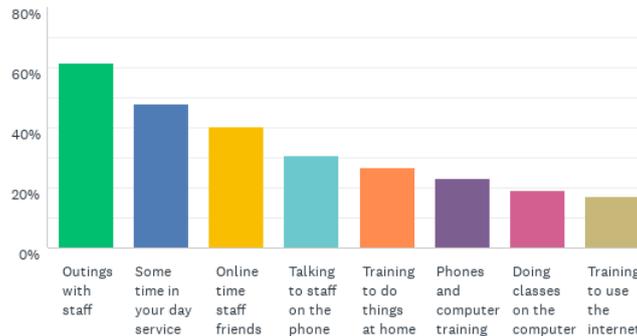
9% of respondents were happy with existing supports

"The service my daughter attends are fantastic. They provide her with an online zoom timetable for activities 2/3 times daily. Bingo, Art, yoga, keep fit and dance. They couldn't be doing more."

"We are very happy with the service at the moment. Activity packs are sent out every 2 weeks, the staff check in most days by phone and there's a variety of online groups and activities on every day."

Direct, face to face supports from their service are also a clear priority for people with intellectual disabilities at this time. Outings with staff ranked most important with more than 60%; some time at the service ranked important for almost 50% and online time with staff and friends was ranked important by 40%.

Q9 What supports do you think would help you the most? (Choose 3 things. Then click OK)



The resumption of day service provision – concerns

Not surprisingly, the single greatest concern expressed by over half of the respondents was the fear of a Covid 19 infection or outbreak within the service. This was coupled with a specific concern that the person who is supported may not understand the need for the social distancing and other Covid 19 restrictions and may not be able to practice them.

“My son cannot understand the idea of social distancing or its importance so I'd be concerned that the risk of infection would be increased or, if it was strictly policed, that he would get angry.”

“My son likes to greet people with a hug or a handshake”

For some people who are supported by the service these restrictions will create anxiety. Others may not be able to tolerate the wearing of face masks.

Similarly, ensuring Covid 19 safety on transport to and from the service was identified as a challenge by many respondents and some had a specific concern that the infection might be carried home to other vulnerable people with underlying conditions or risk factors.

A related concern was about the changing of routines and the upset or anxiety that this can cause. People spoke of the fact that their family members had adapted to a radical change in routine over the past three months and in some cases had regressed. A return to a modified or

restricted service would entail a further significant change in the routines of the day service that they were accustomed to.

“His day service will not be the same again and J will not understand the reason why because of his disability”

“It’s going to be very hard to get my son to mix again or to even go”

A related concern was staff changes and turnover and the lack of continuity in relationships between staff and the person supported.

A further concern named by 18% of the respondents was that the scope of the services provided would be limited and the hours reduced.

“We cannot wait till September. I am extremely concerned that we will not get the level of support we need. Other siblings within the home are stressed due to the situation with a disabled child 24/7 at home.”

As well as impacting on the person and the household, some respondents also expressed concern that it would impact on their own ability to return to work.

“It has been so long, I am not sure my son will want to go back. We have to go back to work soon and he cannot stay home alone as his support needs are so high.”

Respondents identified the need for clear communication with families about the level of service and the likely timeframes for return. Some respondents also identified the need for staff training and expressed concern about the physical infrastructure of the centres and the limitations that this would place on social distancing.

17% of respondents had no concerns about a return to the day service.

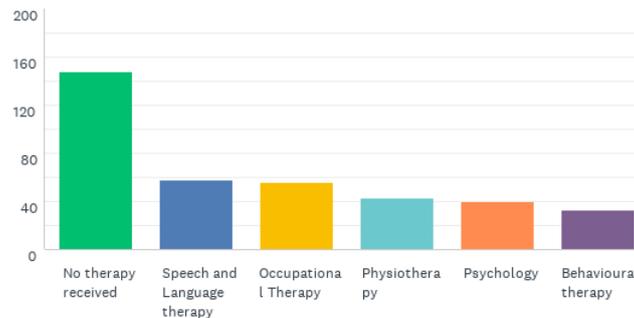
Other supports

Therapy supports

130 respondents (45%) indicated that their family member had been receiving some form of therapy support prior to the Covid 19 crisis. As shown in the chart below, the most common forms of therapeutic support

that people received were Occupational Therapy and Speech and Language therapy.

Q12 Does your family member get any therapy supports in their day service? (tick any that apply)



Only 28 people indicated that they had received some form of online or phone-based therapeutic support since the crisis had started.

When asked about the impact of this change, the most frequently voiced concerns were about the need for support to address anxiety, low mood and behaviours of concern arising from the constraints of the lockdown.

“Increased levels of anxiety, stress and meltdowns. Does not comprehend why he can't see his friends and go to the centre. We have to repeat on an hourly basis the situation we are in while continuously distracting him with activities. It's exhausting”

“Increase in behaviour that challenges during day service closure. Behavioural support by phone from the day service has been essential and very useful.”

Other concerns expressed were about regression and a decline in mobility speech and language, and other physical skills in the absence of regular therapeutic support.

Respite and home support

Prior to the lockdown, 123 respondents (43%) had access to respite and a further 40 (14%) had access to home-based supports. Since the lockdown, only 15 people (5%) had got some respite and 16 people had

got some home-based support. 3 people indicated that they had been offered respite and declined it because of concerns about Covid 19 infection.

This reduction in support combined with the increased stress of the lockdown has had a significant impact, particularly in those situations where the person has high support needs. 28 people (24%) of those who normally get respite or home support, indicated very high levels of stress and exhaustion as a consequence of the loss of this support.

“Absolutely no respite, no day care since the service closed in March. This has had a tremendous impact on all of us, mainly on us, his parents, in managing his 24 hour care ourselves.”

“No respite or home support. Totally exhausted never a minute off. No time for other family members who also need support. Continuous driving to maintain calmness”.

Recommendations

People with intellectual disability and their family members have clearly described the ongoing impact of closure of day services and the resulting loss of supports to people with an intellectual disability. The survey responses tell us these are supports essential for activities of daily life, essential for access to the local community, education, and employment and essential to physical and mental wellbeing, for some essential to function, self-regulate and navigate the day.

1. Timely Re-opening of Day Services – Equality of Access

Guided by and adhering to public health advice, adult day services for people with an intellectual disability should reopen in line with the Roadmap for Reopening Ireland, on a par with equivalent services and facilities for the general population. Day services are education and training facilities for adults including school leavers with disabilities. As set out in the Roadmap for Reopening Ireland, all adult education facilities may reopen from June 29th, 2020.

2. Full Restoration of Services and Supports, in line with New Directions

The resumption of Adult Day Services must not mean a reduction in service hours or supports for people with intellectual disability or a greater reliance on family members or carers.

Almost 40% of individuals who responded to our survey attend day service with support at a level of 1:1 support. A significant number of individuals are supported at a ratio to enable attendance in small groups or cohorts and a small number of respondents 10-15% require little individual support. This level of individual support, combined with the increasing number of smaller community-based settings established under the New Directions policy, should mean that many day services are well placed, with good leadership and governance and the restoration of staff redeployed to other settings at the peak of the crisis, to adapt and work to restoration of services. The full implementation of New Directions is key to ensuring day services are person focussed and so adaptable to the changing needs of the person in this or any other circumstance.

3. Funding for COVID-19 Adaptations

As with other sectors financial assistance will be required for service adaptations to help overcome the challenges created by this health crisis. The Minister for Health must make available COVID specific funding to allow for extra space/premises rental, the cleaning requirements to have safe premises, small works to premises and any additional support staff.

Use of Technology and the Need for Consultation

Where use of technology is proposed for communication or remote support, service planning and development should include a review and consultation to establish

- Existing and available service and community resources
- each individual's access to the necessary technology,
- each individual's capacity to use and benefit from use of technology vs existing support options,
- each individual's interest and preference to use technology vs existing support options

Our consultation indicates that direct face to face supports from their service are a clear priority for people with intellectual disability. There is also a clear preference amongst people who are providing support at home for direct contact with staff and for advice and support, rather than for virtual online contact. Face to face support is the only form of day service that will work for people with complex disabilities.

4. Access to Therapy

45% of respondents indicated that their family member had been receiving some form of therapy support through day services prior to the Covid 19 crisis and the absence of therapy is causing significant difficulties for many. Access to therapy supports must be restored, in a virtual or face to face manner where safe, as a matter of priority.

5. Access to Respite

Some families are struggling with almost no access to respite at present. This service needs to be resumed to allow a break for families who are struggling. In addition, home supports must be reinstated to support people during the day.

6. Day-Service Roadmaps to Re-opening

Clear communication is required, from the HSE and individual disability service providers, on a roadmap to the re-opening of day service provision. Communication should detail reopening dates, schedule for service and support restoration, alternative models of service delivery (where agreed with the individual) and transport provision.

7. Consultation - the Voice of the Person

In line with New Directions any changes or adaptations to service planning or supports must start with consultation with the person with disability and their supporters (if required) and person-centred planning. There should be out of home support available to all people within public health guidelines.

8. Risk Management

The precautions services are taking to prevent the spread and minimise the risk of contracting Covid-19 within the service must be clearly communicated to all attending, working in, or otherwise engaged with the service. Everyone needs to understand their role in protecting themselves and others.

Measures to prevent and mitigate COVID-19 must inform but must not determine the service and support provided to the person with an intellectual disability or their family. Service adaptations must not be at the cost of essential supports to people with intellectual disability.

Conclusions

Disability day services have been closed for 3 months now and there is no concrete date for when they will resume. People with intellectual disabilities and their families are severely impacted by this loss of support. Clear, coherent communication is required around the planning to reopen services and supports.

The closure of day service provision has led to a variable response by services in how they support people. Some people report a high level of satisfaction with the support they are receiving at present. A majority report little, or inadequate support. This is partly to day service staff being redeployed into residential services to combat Covid-19.

Respondents report increases in behaviour of concern, anxiety, loneliness and other moods. Immediate measures are required to support people around the impact on their mental health and wellbeing. On the flip side a lot of people are happier since the lockdown but family members fear this may cause difficulty in them returning to their previous supports.

Given current public health guidance attendance at day services will be restricted in numbers and hours of support. It is of vital importance that the Minister for Health makes temporary funding available to ensure as many people are supported for the greatest amount of time possible upon the reopening of services.

Inclusion Ireland is funded through the Scheme to Support National Organisations to do this work.



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