

Children & Young People with Autism+ Keyworker Evaluation Report

January 2023



1. Introduction & Context

This report is the final piece of work SCVYS has been commissioned to complete in relation to the Autism+ Keyworker pilot project, spanning almost 2 years. It follows on from some initial engagement in 2021 with children and young people to gather their thoughts on the proposed keyworker support roles for those living with autism and / or a learning / physical disability of some kind.

The full initial engagement report from 2021 can be viewed [here](#).

An easy read version summarising the findings and recommendations of the longer report was also created and sent to all those who engaged as well as relevant commissioners within the health sector. This closed the feedback loop, and is available on request.

In November 2022, SCVYS created a “You said, we did” [summary report](#), evidencing the health systems response to those initial findings and recommendations from children and young people back in 2021. The evidence was provided by frontline keyworkers and their managers; however, Commissioners chose not to feed into the report as they felt it might impact on impartiality and accuracy given they are not as close to the operational aspects of the service.

SCVYS was subsequently invited to quote for a further piece of evaluation to undertake interviews with some children, young people and families who had received support from a keyworker. This aimed to understand the impact of that support on them, and to identify anything that could further develop and enhance the effectiveness of the role moving forwards. It also provided the opportunity to test the perspective of health workers that they had indeed responded to the recommendations provided in the original report.

2. Approach & Method

As of December 2022, 50 children, young people and families either had been or are being worked with by the Keyworker project. There are 4 Keyworker roles, 2 with Midlands Partnership Foundation Trust and 2 with North Staffordshire Combined Healthcare Trust. There have been personnel changes within this team meaning that some families have had more than 1 keyworker during their period of support. The support provided spans an initial period of 12 weeks, but can be extended if the need to is evidenced.

SCVYS were given the names and contact details of 14 individuals / families who had agreed to be part of the evaluation. All were contacted with initial details of what was being asked of them, inviting them to respond either affirmatively that they were still keen to engage, or alternatively to let us know if they were no longer willing to take part. On a couple of occasions parents gave some general positive feedback by email or text, which we were grateful for, but we still took the opportunity to request their involvement to ensure we gleaned as much rich, qualitative information as possible. Both did subsequently agree to interviews and provided useful detailed information which would not have been gathered without the follow up communications.

The provision of specific names from the Keyworker Support Team, rather than a more randomised approach, could be questioned, however due to the complexities involved in these family's circumstances, voluntary engagement in the evaluation process is important for two reasons. Firstly, to avoid adding additional stress or

pressure to a family at a potentially difficult time, and secondly, that a willingness to engage would be far more likely to bring good quality feedback and useful information.

Of the 14 individuals/families, 2 actively declined to participate, whilst a further family felt it wasn't the right time due to the current challenges they were facing. 7 families were interviewed and 4 did not respond to or answer any of the emails, texts or calls that were used to invite their participation in the evaluation. Although 7 families might seem a small cohort, it equates to approximately 14% of those supported by the keyworker project, so this is deemed to be a viable evaluation on that basis. 5 of the interviews were with parents/carers, 1 interview was with a young person and 1 interview involved the parent and young person via use of a phone on speaker mode.

SCVYS felt that it was inappropriate to continue to contact those who were non-responsive, as this might inadvertently add to any current anxiety or mental health issues, and so we drew the line at one initial information text/email (offering an opt out by text/email if desired) and 2 follow up telephone calls on different days / times over the following week or so.

This approach was checked for appropriateness with the Keyworker Support Team who also offered to contact families on our behalf to refresh their memory of having agreed to participate in the evaluation, as it was some period of time since the permissions had been initially granted.

SCVYS also tried to widen the scope by sharing the "You said, we did" report with 50 participants from the original engagement exercise who had asked to be kept updated on developments around the keyworker project. An offer was made that if any of them had been supported by the keyworker, we would welcome their involvement. They were given an email and phone number to contact if they wanted to be interviewed about that experience. No one responded to this offer.

2.1 Evaluation Questions

A series of 10 questions were agreed with health practitioners and designed to test whether the keyworker role had been adapted to meet the recommendations of the original report findings.

The first 5 questions focused on the family experience of the keyworker service against the initial recommendations. Questions posed included:

- Q1. *Did your keyworker help you communicate with the professionals that were supporting you?*
- Q2. *Was keyworker support available when you needed it?*
- Q3. *When your keyworker was reducing the level of support being provided, did they talk to you about that, take on board your views, point you to other help and work with you as the support level was reduced?*
- Q4. *Did your keyworker know what other support was available to you, and did they help you to find it?*
- Q5. *Once your keyworker support had finished, did you ever feel that you needed to get back in touch with them for extra help? If so, were you able to contact them again for more help?*

The recommendation around continuing to involve children and young people in the development of the keyworker role was deemed to have been met by the commissioning of this additional evaluation piece.

The subsequent 5 questions were more about the family's experience of how the service had been delivered, the impact and outcomes of the support as well as whether anything could have been better. Questions posed included:

Q6. What were the best things about having a keyworker to support you and your family?

Q7. What could have worked better for you and your family?

Q8. What difference did having the help of the keyworker make to you and your family?

Q9. If you had to choose between continuing the keyworker roles or providing help and support in a different way, which would you choose? If different, what might that alternative kind of help look like?

Q.10 Did you feel the keyworker was person-centred and specific to your needs?





The questions were asked during a telephone call interview arranged for a mutually agreed time. The 7 interviews took on average around 20 minutes. 1 was with a parent/carer and young person, 1 was with a young person on their own and 5 were with a parent/carer. One young person who wanted to be involved but at the very end opted out leaving the interview to be completed with a parent found the process hard due to their heightened anxiety. Another of the young people is non-verbal, and so didn't participate.

3. Feedback from Children, Young People & Families

3.1 Recommendations revisited

Firstly, here is a reminder of the 6 recommendations from the original engagement report that we were testing.

As highlighted above, the final recommendation around continuing to involve children and young people in the development of the keyworker role was deemed to have been met by the commissioning of this additional evaluation piece.

	<p>Keyworkers should help you to work with professionals.</p> <p>Especially with professionals like doctors, nurses and specialists as you said you were most uncomfortable talking to these people.</p>
	<p>Support should be available when you feel you need it.</p> <p>Many of you said you should be able to access help when you feel you needed it. We think that there should be a way for you to get help when you think you need it.</p>
	<p>Reducing help should be done with you and your family.</p> <p>We have suggested that the Keyworker should work with you and your family to decide how long they will support you for. They should also make sure you are asked how they should stop supporting you to make sure you feel ready to become more independent.</p>
	<p>A Keyworker should know of other support for you.</p> <p>We think that Keyworkers hold information about where you can go for help. They could also help find other activities that would be good for you.</p>
	<p>Provide a way for you to get Keyworker support again if you need it.</p> <p>We have recommended that there should be a way to get extra support in the future from your Keyworker if you think you need it.</p>
	<p>Young people should carry on being involved in what Keyworkers do.</p> <p>We think that the health services should make sure that young people who have Keyworker support are able to say what they think about what their Keyworker does.</p>

3.2 Findings

Following transcription of the interviews, these are the key findings presented against the respective questions asked and supplemented by a sample of supporting quotes where appropriate.

Family Experience against Initial Recommendations

Q1. Did your Keyworker help you with communicating, including to the wider group of professionals supporting you?



This question was designed to test whether keyworkers had taken the time to listen and understand, help with communication around needs and wants, provided reassurance and built trust in line with the engagement report recommendations.

Finding: All families felt listened to, understood, communicated with and reassured leading to a trusted relationship with their keyworker. Having someone advocate for you, having fully understood your needs ensured families felt valued. It also helped to progress actions as the keyworkers were able to get a different response from fellow professionals than the parents/carers had been able to.

“ As my son is non-verbal, I have been his voice for 19 years, and she took the time to build my trust and support me. She was there to fight my corner, and I used to vent at her sometimes too when I felt the system was getting too much for me. ”

“ She helped us to understand what was happening and what was being proposed. Took the time to listen and understand our thoughts and feelings. Earned our trust and K felt able to ring or text on her own. ”

Q2. Was Keyworker support available when you needed it?



This question tested whether the keyworker had provided the right kind of support, available at the right time and accessible when needed, again in response to the engagement report recommendations.

Finding: Families felt that keyworker support was often only activated at a crisis point in their lives, rather than as an earlier intervention. Keyworkers are not considered to be a crisis service, although primarily support is targeted at those identified as a red risk on the Dynamic Support Register (DSR). They are also not there to duplicate the role of the Care Coordinator. This raises questions around how families have reached breaking point, without it being flagged with the Care Team who would identify risk and tag this on the DSR. Families recognised that late intervention could be due to the level of resources available. However, earlier help was still viewed as important to families, as some felt it would have been easier to make a difference for them by helping much sooner and may have helped resolve

“ The keyworker support came in a bit late. I felt let down by CAMHS and took an overdose which was a catalyst for greater intervention. In that sense, the system needs to be more agile, more responsive to need, work better together and be more preventative than reactive. ”

the challenges more quickly. The term “*I was at breaking point*” was used by almost all interviewees often at multiple and various points in the conversation with them. Some respondents cited limited responsiveness specifically at evenings and weekends but understood the keyworker “cannot be on call 24/7.” They also acknowledged that support was quickly forthcoming once keyworkers were back at work.

Q3. When Keyworker support was being reduced, did the Keyworkers work with you throughout the transition?

Again, following on from the engagement recommendations, the next 2 questions sought to understand how keyworkers communicated any reduction or withdrawal in support, took on board the concerns of families and if they identified alternative support options that may have been available.



Finding: When support was stepped down, communication has generally been good, although 2 families indicated during the interview, they weren't sure if the support had concluded or not. Whilst for some it was hard to see the support steadily withdrawn, they could see the benefits of growing in independence from intensive support. The young person interviewed particularly highlighted the personal growth they had experienced by learning to stand on their own two feet.

“ The taking away of support was talked about, to see if E could stand on her own feet. With her just starting school, I would have wanted to carry the support on until she is settled, and I am not sure if the support has finished or not, as I haven't heard anything for a couple of weeks. ”

Q4. Did your Keyworker know what other support was available and did they help you find it?

This question was designed to test whether families were signposted to alternative ongoing sources of support beyond this service that could help in sustaining any positive outcomes achieved by key workers.



Finding: Many of the families were involved with multiple statutory support services including Education, CAMHS, Housing and Social Services, and the keyworkers were helpful in navigating the support system which often felt like an impenetrable brick wall. Keyworkers have helped young people find the right educational placement for them including helping one return to college. They have also been a link with CAMHS helping to improve communication and understanding around medication and access. Three respondents also cited accessing VCSE support or activities via Action for Children, Alice Charity and summer programmes.

One parent in particular referenced the importance for her of a local peer support group on Facebook that she had been made aware of.

“ Most helpful thing was a South Staffs CAMHS Facebook group for parents. This has been massively helpful in realising S is not alone. ”

Q5. Once support had finished, did you ever feel you needed to get back in touch with them again for extra help? If so, were you able to?



In the original engagement exercise, children and young people had identified the need for a “safety net” mechanism to be in place once keyworker support was completed, in case of any bumps in the road to recovery.

Finding: Responses to this question tended to have a longer term emphasis. For example, one individual would have welcomed continued support with a housing situation which has been challenging. They acknowledged having the keyworker as an advocate has helped to raise awareness of the issues and get their case on the radar of housing providers but this remains unresolved. Another example cited was support with the transition to accessing adult services which would be helpful once the keyworker support had ceased.

One parent cited it wasn't so much that extra help was needed but because their daughter had forged a strong emotional attachment with the keyworker, they would have valued an occasional check in to provide some light touch reassurance.



As mentioned earlier, in terms of the final recommendation from the initial report, that children and young people should continue to be involved in shaping and influencing the development of the keyworker roles. The commissioning of this additional evaluation would suggest that health colleagues are keen to understand how the service is being received and experienced, and also what can be improved and developed as the keyworker roles become more embedded.

Family Experience & Impact of Keyworker Support

The next 5 questions were designed to understand the impact of the keyworker support on children, young people and families, what worked well and what could have worked better.

Q6. What were the best things about having a Keyworker to support you and your family?

Finding: Those supported felt they had been given a voice by the keyworker, where previously they had felt frustration at being unheard. What also resonated was the keyworker was strongly viewed as an ally who understands and can “*fight your corner.*” Having the keyworker as a single point of contact, who knew the family's story took pressure out of the situation, as those being supported felt they didn't have to keep repeating themselves, that they had someone to recall discussion points whilst ensuring they didn't lose useful information.

“ The keyworker really listened to me, believed me and my experience, took things on board and advocated for me. Sometimes they would speak and it was as if they had read my mind as to what I would have wanted to say. In a short period of time, they achieved a lot with and for us. ”

“ I was tired of fighting when the support arrived, but they took a weight off my shoulders. They helped with the EHCP, got E a place in a special school and helped get the right medication. ”

Q7. What could have worked better?

Finding: The trusted relationships built stand in sharp contrast to the family's perception of a health and social care system that is challenging to understand, difficult to navigate and communicate with, and seemingly virtually impossible to get what you need from it. Phrases used included *"I was just hitting a brick wall."*

One participant reiterated the importance of a preventative approach and the necessity to identify the seriousness of a family's situation earlier whilst not making assumptions that because they have coped before they will be able to again. A further participant highlighted the considerable time it had taken to secure a placement for their child that had already taken 12 months, albeit they did acknowledge this was a whole system issue and not the fault of the keyworker.

Five participants stated there was nothing they would highlight in terms of improvement whilst emphasising the keyworkers *"were so helpful in everything"* and that *"they really do try their best for us."*

Q8. What difference did having Keyworker help make to you and your family?

Finding: It was powerful hearing the stories of families who felt that keyworkers had given them the gift of time, and the trusted relationships which follow show how transformative these personal connections can be in affirming value and worth, combating isolation or feeling like you are battling alone, reassurance of presence and support, listening, understanding and advocating.

“ They lifted my mood with their positive approach, and we trusted them to help us and get things moving. ”

“ I really felt heard by the keyworker. They also helped me with my relationships with my family, which are much better now. On one occasion I needed to get a train to Wales, and they stayed with me past their usual finish time to make sure I was okay and able to get the train. ”

Q9. If you had to choose between the support you received or another way of receiving the required support, which would you choose? If different, what might that look like?

Finding: On the whole families felt they wouldn't have chosen a different type of support, but would have liked the keyworker intervention earlier. They were happy with how the support offer was delivered, particularly the outreach aspect aimed at preventing hospitalisation. Connection into peer support networks was highlighted as a positive supplementary method of support that helps parents to know they are not alone. One parent suggested a facilitated online gaming group for young people as an informal way to build trust and access support (elaborated on below in the recommendations).

Q10. Did you feel your Keyworker was person-centred in their approach taking into account your specific needs?

This was an additional, specifically requested question from the keyworker team to ensure that the support provided was focused on the person/family being supported and their particular situation.

Finding: 100% of participants felt the keyworker took a personalised approach and adapted their support to take account of their specific needs.

4. Recommendations & Conclusion

The keyworker support has been greatly valued by all of the families we spoke with. Keyworkers appear to have largely met the recommendations expressed within the initial report.

- **Continuation of the Keyworker project.** The outcomes are clear, and the experience of families shows how valued this support is with some extremely tough challenges. Some additional flexibility on the intervention timescales should also be considered to ensure the outcomes created are more sustainable over the longer term.
- **Improve clarity of role and identification of risk to enable earlier intervention** for families so that it doesn't feel like crisis support. The communication links with Care Coordinators / Care Teams are crucial in this, as is identifying the current real-time level of risk for all families being monitored.
- **Improved communication** and clarity around the 12 week pathway and route to discharge could be discussed with families on the first day of engagement. Families will then be clear on when support is expected to cease and can be provided with ongoing reassurance about alternative sources of help as they approach their pathway exit. Moreover, clear communication on how they can tap back into support as a safety net if required and any criteria that might need to be met would be beneficial to share.
- **Training and awareness raising for the wider workforce** around truly listening to and valuing the voice of the family. The final interview summed up what others had expressed in various ways. *“As a parent talking to a professional, I continually hit brick walls, but when the keyworkers (as professionals) spoke with other professionals, they were listened to and action/progress was made as a result.”*
- **Continued involvement in the current co-production charter work** being undertaken, so that a tool is in place to help drive improved restorative and person-centred practice across the support system for local children, young people and families.
- **Explore innovative approaches to engaging young people.** For example, whether a closed online gaming group on a platform such as Discord, could enable keyworkers to engage more effectively with referred young people. The theory is that engagement happens whilst involved in a fun activity where they feel safe, rather than what could be viewed as an artificial home visit. This might be particularly effective with young men, as opening up in conversations without the distractions of shared activity or interest is harder. As balance, many of the girls supported connected well with their keyworkers and found shared areas of interest that encouraged dialogue.
- **Connection into peer support networks** should be actively encouraged alongside the creation of new networks where gaps are identified. These networks provide valuable supplementary support, reassurance and confidence to families in knowing they are not alone.

In conclusion, we recognise the benefits of this support service to the families who were interviewed. It has improved outcomes in terms of engagement with education, access to services and family relationships and wellbeing. Families also feel more heard, more understood and that they are advocated for better because of this service. Any improvements or developments identified are viewed as evolutionary rather than revolutionary in nature.

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42a Eastgate Street

Stafford. ST16 2LY

Telephone: (01785) 240378

Email: office@staffscvys.org.uk

Website: www.staffscvys.org.uk