

Neurodiversity & Grief

Working Together To Support Pre & Post Bereaved Children And Young People

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Over the past two years the Child and Adolescent Bereavement Service (CABS) at Harlington Hospice has increased referral pathways by extending partnerships with the North West London - Integrated Care System, Schools, Social services, CAMHS and healthcare professionals in the London Borough of Hillingdon. This joint approach to working has identified significant gaps in bereavement support for clients who are neurodiverse, especially for those with more challenging grief responses where families and schools struggle to understand and manage the impact of death and dying.

What We Do

CABS provides support to children and young people aged 4–17 years and their families, who live in the London Borough of Hillingdon. This service is available to those who have experienced bereavement or have someone close to them with a life-limiting illness.

We offer: individual art therapy sessions, group art therapy, end-of-life support for families, family sessions, parent

support groups, psychoeducation for schools & healthcare professionals, memorial events and creative workshops. Every child and family are different and our Art Psychotherapists aim to find the right approach to help with their needs.

We are an inclusive service, respectful of religious, cultural, spiritual grieving traditions and rituals.

The 'CABS' Team

The Art Therapists in our team have diverse skills and expertise in individual, group and Family Therapy. An Art Therapist (or Art Psychotherapist) is someone who has undertaken approved postgraduate training and is registered with the Health and Care Professions Council (HCPC). We adhere to the principles of inclusivity and we are committed to valuing diversity.



Definition of Neurodiversity

Neurodiversity is a contested term, but for the purpose of our research we have chosen a definition which resonates with our experience and practice as Art Psychotherapists.

Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one 'right' way of thinking, learning, and behaving, and differences are not viewed as deficits.

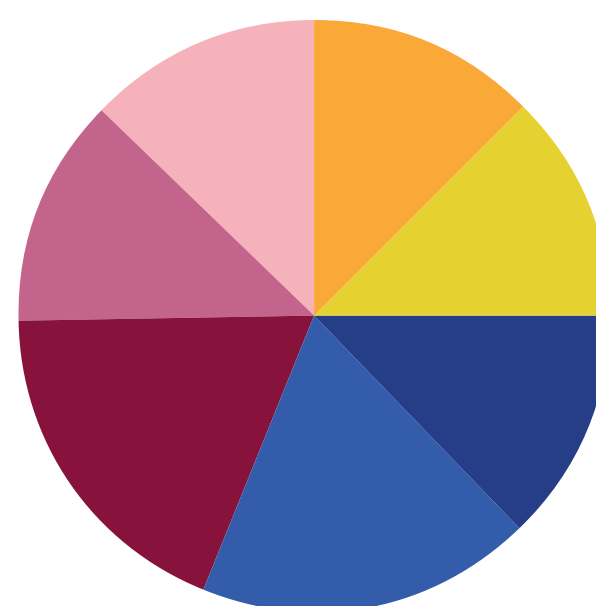
"The word neurodiversity refers to the diversity of all people, but it is often used in the context of autism spectrum disorder (ASD), as well as other neurological or developmental conditions such as ADHD or learning disabilities. Neurodiversity advocates inclusive non-judgmental language".

(Harvard Medical School, Baumer, N., Frueh, J., 2021)

Why?

This is a research project in progress. The topic of neurodiversity and grief is an under researched area of practice. What does the evidence tell us?

- Gaps in provision to support neurodiverse children due to an increase in referrals to the service
- The need for adapting service provision for the needs of neurodiverse clients
- Insufficient understanding of the grief response of neurodiverse clients
- Misperceptions of neurodiverse grief
- Existing health inequalities which need to be addressed for neurodiverse clients
- Lack of education on grief for parents/carers of neurodiverse clients
- The deficits of training in this area for the professional therapist community
- The need for collaborative and integrated approaches with all agencies involved in care



- 13% – Anger
- 13% – Numbness
- 16% – Communication barriers
- 19% – Anxiety
- 13% – Avoidance
- 13% – Fixating on death
- 13% – Fear of forgetting

Our Aims

- The aim is to improve bereavement service provision for neurodiverse clients.
- To develop collaborative ways of working with a wide range of agencies involved.
 - To analyse the existing research and evidence.
 - To reach out to the professional community to identify barriers and challenges.
 - To provide evidence-based creative therapy support for neurodivergent bereaved clients and their families who are isolated in their grieving processes and the professionals working with them.
 - To understand the need for psychoeducation support groups for parents/carers who struggle to manage and understand the more challenging aspects of neurodiverse grief.

Methods

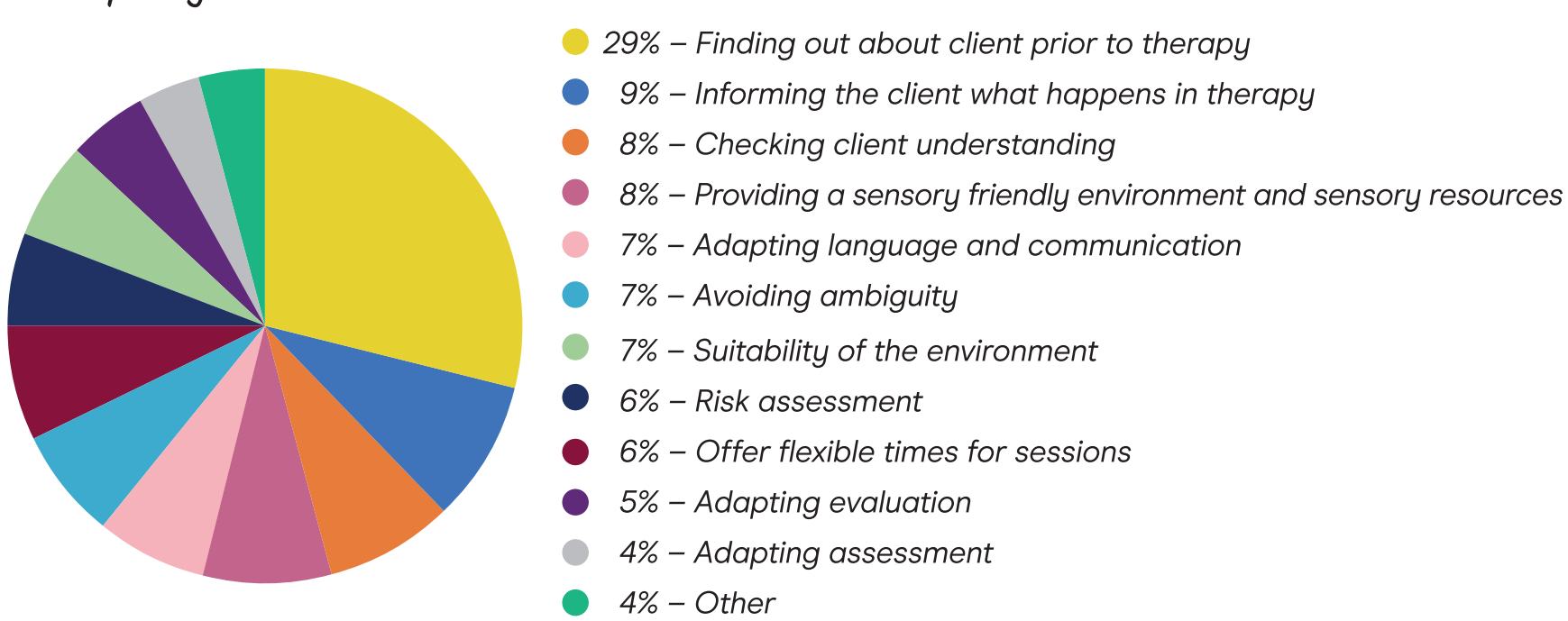
- At this stage in our research, we have conducted the following:
- Facilitating psychoeducation support for schools, social services and professionals involved in the YP care.
 - Conducting a systematic review of literature on this topic.
 - 50 Art Psychotherapists completed a survey about their experience of adapting practice with neurodivergent clients, their training needs and levels of confidence in this area.
 - Working on adapting practice to the needs to neurodiverse clients.
 - Providing psychoeducation groups for parents and carers.

The Results

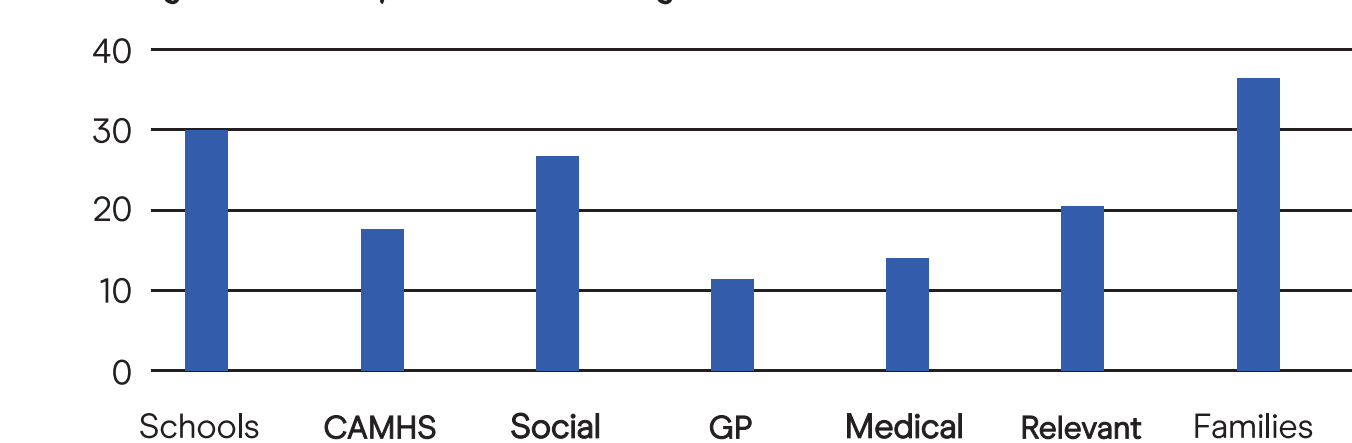
1: Identifying the ways Art Psychotherapists address bereavement and neurodiversity:

- Together with the British Association of Art Therapists we conducted a survey with the purpose of collating information about the ways art therapists address bereavement and loss with neurodiverse clients. Our findings are:
- 58% of Art Psychotherapists felt less confident working with grief and neurodiversity
 - 81% had not received specific training in this area
 - 50% were familiar with the concept of neurodiversity
 - The info graphics display collaboration patterns and how therapists adapted practice to client need

Adapting Practice To Neurodiverse Clients Needs



Art Psychotherapists Working in Collaboration



2. Collaboration with schools, social services and professionals

- Psychoeducation and training sessions for schools
- Advocating in 'Team around the child' professionals' meetings
- Providing recommendations and advice to schools and professionals about each client

3. Literature review

- Review research papers on the impact of bereavement therapy for neurodiverse clients
- Review research papers on adapting services for neurodiverse clients
- Review research papers on neurodiverse affirmative language

4. How our service adapted its provision to meet the client needs

- Assessed the suitability of the environment
- Adapted evaluation and assessment procedures
- Carried out risk assessment for each client
- Involved a family member or carer
- Provided sensory resources
- Started using neurodiverse affirmative language
- Offered flexible times for therapy
- Introduced regular team reviews to improve therapists' confidence

5. Parent Psychoeducation group

- Identifying barriers for starting conversations around death and dying
- Introducing grief models
- Offering strategies for managing challenging behaviours
- Examining the impact of challenging behaviour for parents and carers
- Organising monthly parent groups to reduce isolation and to facilitate peer support

Feedback from Stakeholders

'Our student now has the ability and confidence to speak to me about things worrying him or making him sad, including the death of loved-ones. This is something he was never able to do before. Recently, during a class session he turned to me and asked, "Miss, is your mum dead?" I answered that sadly, she is and he went on to tell me about his relative. We spoke openly about death and he was happy talking. The student asked me if we could watch the Disney movie, 'Coco' together which has spirits and skeletons as the characters. I can see he now has more of an understanding of death and knows that he can speak about it, and ask questions'.

School

'The grief education group has definitely helped; it has made me think more about how my son might see and feel his grief. I feel he has been punished for his grief in the past in his school because of his behaviour. I know now that it's not that he's acting difficult, it's his feelings of sadness and loss'.

Parent/Carer

'I liked when we talk about neurodiversity in positive terms such as continuum, rather than talking about neurodiversity in terms of disorder or deficits'.

Parent/Carer

'When I am quiet in school or want to be on my own it usually means I am thinking about my dad. I realise that I might feel angry and that is ok. I now have a code word for my grief which I tell my family, teacher and friends'.

Child (11-year-old)

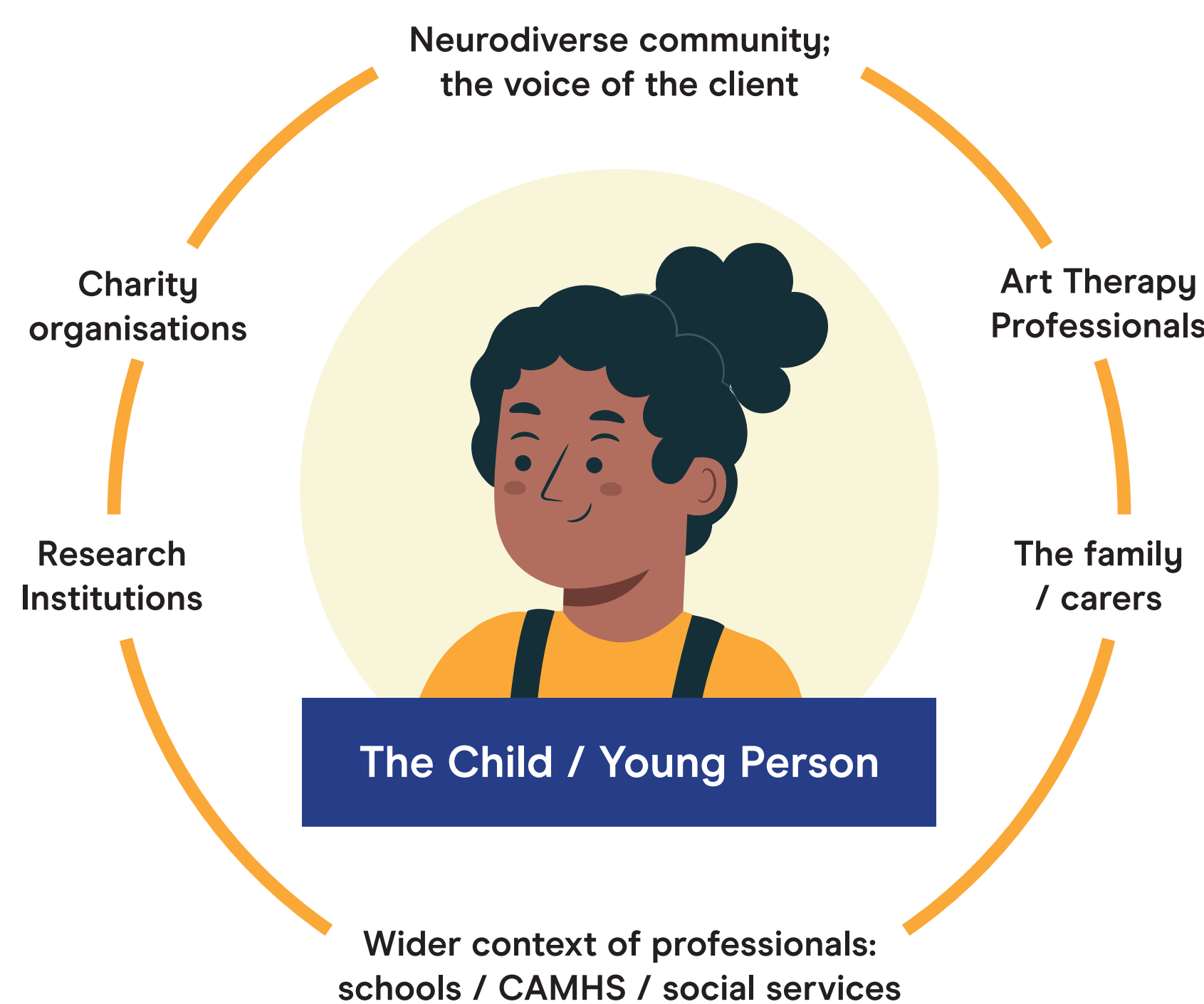
'I would like to find out more about our perceived understanding of grief, and grief processing in a therapeutic context, as it may be different for neurodiverse clients. How does the family understanding of grief impact on their neurodiverse child? Perhaps also the importance of social and cultural aspects of death, ritual and rites of passage, and how a neurodiverse client may engage with these, or not'.

Art Psychotherapists

'I don't feel as angry now, my emotions are not as high. Talking about my feelings in the therapy sessions has helped me, I didn't really do it before. I have learned a lot about myself, not everyone thinks the same way, I expressed my grief with anger and thought this was weird, but now I know it was part of my grieving and I know myself more'.

Child (17-year-old)

Working Together To Support A Child Or Young Person



Conclusion

By working in partnership, the service saw a 37% increase in referrals for neurodiverse clients in 2022. We have identified the gaps in knowledge and skills in the professional community, including therapists, education providers and specialist neurodiversity services. The survey conducted with Art Psychotherapists evidenced the need for specialist training and further research in this area.

By providing psychoeducation for families and schools, we recorded the benefits of talking about death and dying, which helped with changing attitudes towards grief

responses and behaviour. Parents and carers attending psychoeducation groups reported increased confidence with new strategies in coping with their children's reactions to grief and loss.

We have demonstrated that taking an adaptable approach to art psychotherapy with grieving neurodiverse children and young people has increased levels of confidence and competence for our practitioners.

Promoting the service with multiple key partnerships has significantly increased pathways for referrals for neurodiverse clients. Collaborative work has elevated awareness, enabled service growth and led to new learnings for the CABS team and the wider network involved. We recognise that forming partnerships has reduced pressure on additional services and has led to a more inclusive provision of bereavement therapy for neurodiverse children and young people.

Future Plans & Limitations of the Current Project

- Developing training to support schools & families
- Designing research in this area including the voices of service users
- Collaboration with University College London (UCL)
- Recognising the role of the neurodiverse Art Psychotherapists
- Understanding the role of Art Psychotherapy in bereavement provision for neurodiverse