Respect4Neurodevelopment (R4N) Autumn Workshop 2024

Introduction

The R4N Autumn Workshop 2024 served as a significant platform for addressing the evolving landscape of qualitative research within neurodevelopmental disorders, particularly autism. Led by Dr. Felicity Sedgewick and Sarah Douglas, the workshop highlighted the critical need for re-evaluating traditional categorical diagnoses that are often inadequate for predicting developmental outcomes, treatment requirements, and understanding the underlying mechanisms contributing to these disorders. This report aims to encapsulate the rich discussions and key insights shared during the workshop, ensuring that those unable to attend are fully informed of the important developments and collaborative efforts aimed at improving research and clinical practices in this vital area.

Goals of precision medicine for autism

A prominent theme of the workshop revolved around the pursuit of precision medicine within autism research. The speakers asserted that relying solely on categorical diagnoses does not suffice for accurately forecasting developmental outcomes or identifying the appropriate support needs for individuals on the autism spectrum. The workshop urged a paradigm shift towards a more nuanced approach that emphasizes identifying new treatment targets and relevant biomarkers that could significantly enhance personalized treatment strategies. This evolution is largely motivated by the pressing need for improved reliability in biomarker discovery and a concerted effort to enhance the signal-to-noise ratio in research findings. One of the critical objectives articulated during the workshop was to tackle the limitations associated with traditional one-time assessments commonly employed in longitudinal studies. Participants recognized the necessity for more frequent assessments conducted in naturalistic environments, enabling a more comprehensive understanding of individual needs and experiences over time.

Engaging multi-disciplinary communities

The workshop placed significant emphasis on the importance of fostering collaboration among a diverse array of disciplines, which includes engineers, psychiatrists, psychologists, neurodivergent communities, ethicists, and healthcare providers. Such a multi-disciplinary approach is deemed essential for stimulating innovative solutions and ensuring that research priorities align with the needs and preferences of the communities being served. The speakers also shared personal

insights regarding the experiences of PhD students working within smaller laboratory settings, bringing attention to the various challenges faced in accessing cutting-edge technologies and participant pools. This workshop underscored the necessity for building a robust and supportive research community where knowledge, expertise, and resources are shared effectively, thereby enhancing the overall quality and impact of research initiatives.

Understanding neurodiversity and neurotechnologies

A substantial portion of the workshop discussions centered on the concept of neurodiversity, which encompasses a spectrum of neurodevelopmental conditions, including autism, ADHD, and various intellectual disabilities. Prof Eva Loth (King's college London) offered a comprehensive definition of neurotechnology, characterizing it as any technique or device specifically designed to interact with human brain activity, thereby emphasizing its pivotal role in both research and clinical treatment contexts. Additionally, the workshop introduced a neurodiversity-affirmative approach to precision support, which aims to acknowledge the inherent variability in human brain function.

This framework seeks to reduce the stigma traditionally associated with the deficit models of understanding neurodevelopmental disorders. The facilitators outlined the four foundational pillars of the Respect4Neurodevelopment (R4N) working groups, focusing on responsibility, reliability, scalability, and personalization in the development and implementation of neurotechnologies aimed at supporting individuals with neurodevelopmental disorders.

Part 1 - Qualitative Research Stream with Dr Felicity SEDGEWICK and Sarah DOUGLAS

Qualitative research methods in neurodiversity

Dr Felicity SEDGWICK a senior lecturer in psychology of education at Bristol's University and Sarah DOUGLAS a person with neurodevelopmental disorders and researcher at Bristol's University elaborated on the historical evolution of qualitative research methods pertinent to neurodiversity research. They traced the shift from an early focus on autism and related disorders, often mired in deficit-based medical models, towards a more participatory research culture that prioritizes and elevates the voices of neurodivergent individuals.

Various qualitative research types of documents were examined, including traditional approaches such as interviews and document reviews, as well as innovative creative methodologies that incorporate art and music. The speakers placed considerable emphasis on the necessity of carefully designing interviews to cultivate a trusting and supportive environment, especially when

working with vulnerable populations such as individuals with neurodevelopmental disorders, who may have previously encountered mistrust in research settings.

Furthermore, the workshop offered valuable insights into diverse qualitative analysis methods, including thematic analysis, interpretative phenomenological analysis, and grounded theory. The importance of co-production was highlighted as an integral aspect of qualitative research, underscoring the need for individuals with lived experience to play a vital role throughout the research process, from conceptualization to dissemination.

Co-production and ethical considerations

The workshop prominently featured discussions around the vital role of co-production in research initiatives involving neurodivergent communities. The speakers strongly emphasized that researchers must strive to establish partnerships with autistic individuals, ensuring their perspectives and insights are not only welcomed but actively integrated into every stage of the research process. Dr Felicity SEDGWICK, a senior lecturer and researcher, and Sarah DOUGLAS, a person with neurodevelopmental disorders, actively participated in the discussions, making the exchanges all the more enriching for the participants. This underscores the value of replicating such an approach in future similar seminars.

The ethical considerations pertinent to conducting research with vulnerable populations were also a focal point. The speakers articulated the necessity for researchers to embody relational, empathetic, and self-reflective practices, with an acute awareness of their emotional processing. This self-awareness is crucial, as researchers often engage with individuals who may have experienced significant trauma or marginalization.

To safeguard the integrity of the research process, the workshop advocated for prioritizing self-care among researchers, allowing them to engage in research with compassion and professionalism.

Qualitative analysis approaches

Thematic analysis and framework analysis are two integral qualitative research methodologies that play a pivotal role in understanding neurodevelopmental disorders, particularly in the context of autism.

Thematic analysis

Thematic analysis, as defined by Braun and Clarke (2006), is primarily concerned with identifying and analyzing themes within qualitative data. It encompasses a systematic approach, which involves several key phases.

Initially, researchers immerse themselves in the data through familiarization, which entails thoroughly reading interview transcripts or collected data to grasp the content fully. Following this, they generate initial codes to highlight significant features of the data that are pertinent to the research questions. The next steps involve searching for themes by grouping these initial codes into broader categories. Researchers then review the themes to ensure they accurately reflect the dataset before defining and naming each theme, ultimately summarizing its essence without merely describing it (Braun & Clarke, 2006) .

Step	Description
1/ Familiarization with the data	This includes transcription, reading and re-reading the data to gain a deep understanding of its scope.
2/ Generating initial codes	Identifying interesting elements in the data and systematically organizing them by creating initial codes that captured the essence of the data.
3/ Searching for themes	Grouping the codes to form meaningful broader themes that represent overarching patterns in the data.
4/ Reviewing themes	Ensuring that themes are coherent both with data extracts and the entire data set.
5/ Defining and naming the themes	Refining the themes to ensure they are clearly defined and relevant to the research, summarizing its core essence without merely describing the content.
6/ Writing a final report	Presenting a coherent and compelling analysis into a cohesive report, illustrated by relevant data extract

An important aspect of thematic analysis is recognizing when data saturation has been reached, meaning no new themes are emerging. However, it is not necessary to achieve full saturation in every analysis; the key is knowing when to stop. This method remains particularly effective for exploring lived experiences and opinions across diverse participant groups, as it allows researchers to identify meaningful patterns on a broader level.

Case study for implementing thematic analysis: Process of the Sexual Violence Project

This report outlines the implementation of thematic analysis within the "Sexual Violence Project": focusing on the experiences of 24 autistic participants, this project aimed at understanding the nuances of sexual violence in this population, utilizing a qualitative research design to gather and analyze participants' narratives.

The planning stage was initiated by Sarah DOUGLAS, who shared her personal experiences related to sexual violence, highlighting the need for further research in this critical area. Recognizing the gap in knowledge, Dr Felicity SEDGWICK sought funding opportunities to support the research endeavor. During this phase, the team established the significance of the study and its potential impact on the autistic community.

During the application stage, Sarah DOUGLAS and Dr Felicity SEDGWICK collaboratively determined the focal points of the study to ensure a well-defined research question. Dr Felicity SEDGWICK drafted the initial application proposal, while Sarah DOUGLAS reviewed and provided feedback on the content. Their discussions included critical aspects such as specific wording, ethical considerations, and what elements should be included to enhance clarity and impact of the proposal.

For data collection, the researchers actively advertised the study through online platforms, including Twitter and university channels. Dr Felicity SEDGWICK conducted interviews, sending participants the questions in advance and ensuring that various support options were available throughout the process. This approach facilitated an inclusive environment for participants, encouraging open and honest discussions. The interviews were conducted via Zoom, and Dr Felicity SEDGWICK meticulously checked the Zoom transcriptions for accuracy.

The data analysis phase involved a comprehensive review of all transcripts. Both researchers read the transcripts and engaged in separate initial coding, identifying themes and subthemes within the data. They discussed their findings through email communication and organized meetings to create consensus themes. This collaborative approach allowed for a rich exploration of participants' experiences and insights, ensuring that diverse perspectives were included in the analysis. They could then implement Thematic Analysis using the method described above.

Dr Felicity SEDGWICK led the drafting of the manuscript, with Sarah DOUGLAS providing valuable quotations and insights throughout the writing process. The paper was submitted with a joint authorship, enabling both researchers to collaborate on addressing reviewer comments, which further refined the analysis and enhanced the manuscript's clarity.

The "Sexual Violence Project" provides a valuable case study for implementing thematic analysis in qualitative research. By focusing on collaborative practices, rigorous analysis, and ethical considerations, the researchers provided meaningful insights into the experiences of autistic individuals about sexual violence. This approach emphasized the importance of thematic analysis as a flexible and comprehensive methodology in understanding complex social issues.

Framework analysis

Framework analysis offers a structured approach particularly appropriate in applied research contexts such as public health and policy evaluation. Originally developed for systematic policy analysis, framework analysis is distinguished by its ability to compare and contrast data across participants. Additionally, it accommodates a broader range of document types, offering greater flexibility in handling information, making it especially well-suited for studies that requiring the analysis of diverse sources.

The framework analysis begins with familiarization with the data, followed by identifying key themes. Researchers then index the data, assigning codes to themes and subthemes, and subsequently chart the data into a matrix format. This enables a clear visual representation on how participant responses align with identified themes.

Step	Description
1/ Familiarization with the data	This includes transcription, reading and re-reading the data sample used to create the framework, to gain a deep understanding of its content.
2/ Identifying key themes and creating the framework	Starting with overall themes to then identify sub themes and creating the framework from a sample of the dataset.
3/ Indexing	Throughout the entire dataset, codes are assigned to each subtheme and theme, linked to corresponding quotes within the data.
4/ Charting	To have an overall view of each theme among the dataset: Creating a matrix gathering all identified themes and subthemes in columns, and grouping all participants/data items in rows.
5/ Interpretation and mapping	Using a thematic map, linking themes and subthemes to refine them. Responses can also be grouped in typologies (participants answering in the same themes can be grouped into a particular typology). Then, this is possible to create a final notice explaining themes, categories and typologies

Framework analysis is particularly advantageous when working with larger datasets, as it facilitates the examination of cross-sectional data, making it well-suited for mixed-methods projects. One of its key strengths lies in the early development of a framework based on a sample of the data, which is then applied and refined to ensure it adequately explains the entire dataset. This approach provides greater clarity in categorizing responses and identifying typologies within the data. However, it may be less effective for exploratory research where the data is less structured or highly variable. This structured technique is also helpful for larger research teams, as once the framework is defined. It can also be facilitated by the use of software such as NVivo, which can be particularly useful for larger datasets or larger research teams as it gathers all the codes among the dataset.

Case study for implementing framework analysis: HEI Policy Review

This report outlines the implementation of framework analysis in the context of reviewing policies of Higher Education Institutions (HEIs) related to autism. The study aimed to assess the quality and detail of existing policies, contributing to a better understanding of how autism is addressed within educational frameworks.

The research team reviewed the publicly available websites of 132 HEIs in the UK. A preliminary pilot study established 10 key terms related to autism, which guided the subsequent searches. The focus was on identifying relevant policies as well as supplementary materials, such as research articles, blogs, and staff profiles. A comprehensive policy appraisal was conducted using a disability and inclusion-based policy analysis approach, resulting in the formulation of 14 questions to assess the quality of each policy.

Based on existing literature and theoretical concepts related to autism policy, authors conducted framework analysis and developed an initial framework consisting of themes and subthemes. This framework was designed to capture and explain the patterns observed in the data from a sample of the dataset. Then, a quality review of the selected documents was conducted to ensure they met the criteria for analysis, leading to the second stage of framework analysis. When the extent to the whole dataset happened, a research assistant was responsible for the initial coding of the policies, categorizing the data into the predefined themes of the framework.

The analysis revealed that policies generally tended to be relatively poor in specificity, often treating autism merely as an example of disability without addressing the unique needs of individuals with autism. The review identified a wide range of policies that covered various aspects of university life. The most comprehensive detail was found in areas related to practical adjustments and

employment, while there was significantly less detail regarding social support and general inclusion for autistic individuals.

A crucial aspect of the framework analysis was ensuring inter-rater reliability. Multiple researchers independently coded the data, created frameworks, and compared their findings to achieve consistency in analysis. This collaborative approach enhanced the validity of the research.

The HEI policy review serves as a practical case study for implementing framework analysis in qualitative research. By following a systematic approach, the researchers were able to uncover critical insights into how autism is represented within higher education policies. This methodology not only provides a comprehensive understanding of existing frameworks but also highlights areas for improvement, ultimately guiding future policy development in the field of autism support.

Conclusion

Both methods of analyses require careful consideration of validity and reliability. In thematic analysis, validity pertains to the accurate representation of the data, while reliability involves ensuring that multiple researchers can arrive at similar codes and themes. Framework analysis shares these concerns but places an additional emphasis on the rigorous comparison of coded data to enhance the robustness of the findings.

When choosing between these two methodologies, researchers should consider their research objectives, the nature of the analyzed data, and the specific contexts in which they are operating. Thematic analysis excels in deeply exploring individual experiences, while framework analysis is preferable for studies that require systematic categorization and comparison of data across a broader range of participants. Ultimately, both methodologies serve as essential tools for qualitative research, contributing to a more nuanced understanding of neurodevelopmental conditions and informing practices that support neurodivergent individuals.

Part 2 - Plenary

1. **Exploring early brain development with advanced MRI methods (Tomoko ARICHI - Professor at Kings College, London - Head of Department of Early Life Imaging)**

To introduce his research, the speaker highlighted the crucial importance of early brain development. For instance, the differences in brain development between a 28-week-old fetus and a 36-week-old fetus are greater than those observed between a 3-month-old child and an adult. It is

also known that preterm birth has a significant impact on neurodevelopment: two-thirds of very preterm infants present some form of disability, including cerebral palsy, or more commonly cognitive and behavioral disorders. Establishment of long-range connections seems to occur during the last trimester, which can explain that preterm birth leads to significant changes in within-network connectivity and that it can predict later behavior. These alterations in connection patterns may serve as biomarkers for early diagnosis of ASD. Studying this critical window of brain development is therefore an essential challenge and there are few methods available, with most findings coming from post-mortem samples. Imaging techniques such as MRI are therefore necessary to deepen the knowledge on this critical period.

MRI is a non-invasive neuroimaging technique that provides, without ionizing radiation, an excellent soft-tissue contrast with a quantifiable signal, usable for statistics and for prognosis to guide treatment. MRI images are composed of voxels which provide information about magnetic properties of the tissue. The acquisition can therefore be fine-tuned to focus on specific aspects, such as structural or functional properties. This imaging technique permitted to demonstrate the relation between volume in some key structures and degree of prematurity (for instance: reduction in thalamic volume in premature infants).

A specific MRI technique employed is diffusion tractography. Diffusion tractography studies how molecules diffuse (either isotropically or anisotropically) in the brain, enabling researchers to delineate specific nerve fiber tracts and assess how they are affected by diseases or treatments. It can also be used for neurosurgical planning or for prognostic information.

Finally, a focus was made on functional MRI (fMRI), a technique which allows visualization in-vivo whole-brain brain activity, with a relatively good temporal specificity and an excellent spatial information. fMRI is widely used in psychology and neuroscience to identify brain networks involved in different tasks and to track how these networks evolve during development. This technique demonstrated that newborns are capable of forming Pavlov associations or that resting state networks are developed before term.

2. Improving MRI scanning in childhood epilepsy - the day, the scan, the scanner (Jonathan O'MUIRCHEARTAIGH - Reader in Developmental Imaging at Kings College, London)

Imaging processes with children presents many challenges. To acquire high-resolution images, patients must remain still for long periods, which is particularly difficult with children. Additionally, higher-resolution machines are often larger and more intimidating for young patients. Finally, another significant challenge is finding healthy controls, as many parents are reluctant to allow their children to participate in trials.

These issues are sources of limitations in research. For example, in the context of surgical epilepsy, neuroimaging data are mainly based on studies in adults, whereas 75% of people with the condition experience onset and interventions during childhood. Therefore research should shift the focus on assessments during childhood.

Several strategies can help address these challenges. Some of them aim at making the scanning environment more welcoming for the children, and compatible with typical motion occurring during imaging processes.

- A study carried out on a cohort of children aged 3 to 7 years-old showed that a pre-MRI preparation procedure was associated with a 91% acquisition success rate. Considering imaging costs (e.g. around 500£ per hour, requiring large multi-disciplinary teams - with physicists, radiographers & researchers), increasing the success rate of scans in children is critical. Pre-MRI preparation can be done using videos or showing the process for an object with emotional positive valence (for instance, a teddy bear) in a game-context. Involving parents in this process is also crucial to avoid transferring their worries to their children. Furthermore, the language used should be adapted to the young audience, and use of reinforcers is also recommended.
- Another effective strategy is to make the scanner appear more fun (for example by transforming it into something like a rocket or a castle), turning the experience into a game.
- Using a transfer set-up or pad with earphones may increase the success rate of the imaging process.
- Finally, some time-windows seem to be more favorable: doing the scanner at night for babies or toddlers.

When preparing the children is not effective enough, the movements-induced perturbation of the signal acquisition needs to be addressed, in particular using computerized correction of the images.

In conclusion, the speaker emphasized that research should prioritize adapting scanning technologies to account for children's movements, rather than focusing solely on keeping children still during the imaging process.

3. Moving from deficit-based to neurodiversity-affirmative frameworks for understanding early autism (Emily JONES - Professor of Developmental Translational Neuroscience at Kings College, London)

The speaker considered neurodiversity within the spectrum of variation in human neurocognitive functioning. Therefore, autism should not be considered as a disease but a difference, as it is part of the spectrum of human variation. This diversity, resulting from the unique wiring of the brains of autistic individuals, can enrich society and provide collective benefits. The social relational model, developed by Thomas et al. (2004), suggests that the perception of autism as a disease can create subsequent disorders: this perception may be a barrier to thriving, inducing oppressive social reaction and stigma.

The speaker highlighted the impact of ASD and ADHD on quality of life, emphasizing the need to understand early life development. Genetics and diagnosis are correlated, but genetic factors alone do not determine the occurrence of the disorder: Most of them only increase the risk situations. Genetic factors can lead to changes in brain development, affecting behavior, but environmental factors also play a significant role. For example, individuals with an older sibling with ASD have a 20-fold increased risk of developing ASD, influenced by both genetic and environmental factors. To better understand ASD research, it is essential to record environmental influences, brain development, physiology, impacts on behavior and cognition, as well as genetic and epigenetic factors.

Therefore, when teaching children with ASD how to act, it is critical to consider which behaviors are adaptive, to reinforce them, and which are maladaptive, and how to address them. These changes can be supported with interventions aimed at mental health, communication skills, social care, and anxiety management. To understand which interventions truly improve the quality of life for individuals with ASD, community insight is crucial.

One major challenge with ASD is diagnosis, as early diagnosis is quite challenging. Early identification is crucial to maximizing the impact of proposed interventions:

- Exploring social attention to faces provides interesting perspectives. Indeed, gradual changes in social attention to familiar and unfamiliar patterns have been observed, with an increase in neurotypical children and a decrease in those with ASD during the first years of life. It has also been observed that the brain activity induced by social visual stimuli is reduced in individuals at risk for ASD.

- Differences in response to sensory stimuli seems also to emerge early: in 10-month-old children with a subsequent ASD diagnosis, a study did not observe progressive reduced brain activity after repeated exposure to the same stimulus, contrary to same-aged neurotypical children

- Moreover, sleep differs in infants with later ASD: between 10 to 14 month-age, most neurotypical children sleep throughout the entire night, whereas most same-aged ASD babies do not.

It is important to note that many of these disorders can impact one another.

Therefore, ASD phenotypes arise from child-environment cascades. To understand them, we need to measure both short- and long-term temporal dynamics. The goal should be to improve outcomes for people with ASD without losing sight of how neurodiversity can enrich society.

Conclusion

In conclusion, the R4N Autumn Workshop 2024 provided invaluable insights into the multifaceted challenges and promising opportunities present in qualitative research within the realm of neurodevelopmental disorders. The robust discussions centered on precision medicine, the significance of multi-disciplinary collaboration, and the integration of neurodiversity perspectives signal a meaningful advancement towards enhancing outcomes for individuals with autism and related conditions.

As researchers and practitioners operating in this vital field, it is imperative to continue fostering inclusive and ethical research practices that prioritize the authentic voices and lived experiences of neurodivergent individuals. The profound discussions and insightful findings shared

during this workshop are poised to guide future research endeavors and contribute meaningfully to the development of more effective support systems for these communities.

Part 3 Take home messages

- <u>Thematic analysis</u>: A qualitative method to identify and organize themes in data, flexible and applicable to various theoretical frameworks. The six key stages are data familiarization, generating codes, searching and reviewing themes, defining themes, and writing the final report. It requires deliberate methodological choices to avoid bias.

- <u>Framework analysis</u>: A structured method for applied research, using five stages (familiarization, framework development, indexing, creating thematic charts, and synthesis) to organize and interpret large amounts of qualitative data. It is especially effective for team-based studies.

- <u>Co-production and neurodiversity</u>: Participatory research with neurodivergent individuals highlight the importance of inclusion, flexibility and authenticity in research. It leads to more relevant outcomes by offering an equal role to those directly involved.

- MRI techniques can be used to understand the different wiring of ASD brains, these differences can be observed early, providing support for diagnosis.

- While MRI can have promising results, long-shot imaging can be complicated with children. To help with that: making the scanning environment more welcoming and correcting the movement-induced imaging artifact are interesting

- Considering the way children with autism interact with their environment may be provided keys for improving early diagnosis.

In summary, while these qualitative and imaging methods vary, they emphasize the importance of adaptability and rigor in data analysis for producing meaningful and inclusive results.

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