Systemic Inequities in Healthcare: Lessons Learned from Black People with IDD and their Care Partners

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ABSTRACT

Background: Black people with intellectual and developmental disabilities (IDD) are disproportionately impacted by health disparities and endure distinctive systemic challenges as a result of their intersecting identities.

Objectives: This manuscript describes a collaborative project between university researchers, people with IDD and their care partners, and providers to understand contextual and individual characteristics that influence equitable health services access and use.

Methods: The project follows a critical participatory action research approach to address issues of power and equity at the intersections of race, gender, and disability. Data collection strategies included individual semi-structured interviews and focus groups, as well as interactive activities to facilitate deeper discussion.

Lessons Learned: We describe strategies to manage challenges of delayed recruitment, power sharing, equitable and inclusive engagement, and dissemination.

Conclusions: Lessons learned underscore the diverse experiential expertise of Black people with IDD, their care partners, and providers in the co-creation of knowledge, the importance of opportunities for partners from different stakeholder groups to cultivate relationships as part of the research process, co-reflexivity as instrumental to assessing and reassessing engagement processes in real time, and implementation of inclusive strategies for participation in dissemination activities.

KEYWORDS: critical participatory action research, developmental disabilities, intellectual disability, health services, structural racism

Disparities in measures of health and healthcare access for racially minoritized people in the United States persist, and reflect the tangible effects of racism that permeate system, structural, policy, and interpersonal levels. 1-2 Across the lifespan, Black people specifically have demonstrated poorer outcomes than their white counterparts in health categories including, but not limited to, maternal and infant mortality; childhood obesity and asthma; mental healthcare access for teens and adolescents; adult medical care for chronic illness; cancer screenings and care; and overall decreased life expectancy. 1,3-4 Disparate effects of the COVID-19 pandemic brought renewed interest to health disparities in minoritized populations, in particular the enduring challenges of service access. Scholars noted that access inequities were exacerbated when a person is racially minoritized and disabled 3-4; yet, a substantial gap in research to address the specific healthcare concerns and needs of this community remains.

Black people with intellectual and developmental disabilities (IDD) are disproportionately impacted by health disparities.⁵⁻⁷ Scholars have documented disparate outcomes in health services use and expenditures, noting that more than 50% of Black people with IDD are reported to have poor to fair health and only 9% have private insurance.⁸⁻⁹ Furthermore, 9% to 29% of Black people with IDD have significantly lower odds of receiving any services than white patients,¹⁰ while also experiencing racialized differences in how much time practitioners engage in discussions about healthcare transition planning and supports.¹¹ These disparities constitute a net impact on quality of life outcomes for racialized and multiraced people with IDD.¹² While Medicaid home and community-based services are theorized to improve equity and benefit people with IDD and their families (e.g., reduce unmet healthcare needs),¹³ race-based inequities persist in waivers for Black people with IDD in North Carolina

(NC), ¹⁴ California, ¹⁰ and Pennsylvania. ¹⁵

Black people with IDD and their families encounter distinctive systemic challenges as a result of their intersecting identities (i.e., being Black, disabled, etc.)³ and often describe their challenges as a constant struggle marred with racism and ableism. ¹⁶ At the intersections of these identities is the lived experience. Not only do these identities help to characterize who people are, negotiating them can contribute substantially to how a person seeks and receives health care. 17 In their study with Black and Latinx adults with IDD, Li et al. 18 conveyed that healthcare access challenges are different for this group than their white counterparts, and in particular, foregoing medical care due to distrust of physicians. These revelations further underscore the critical need for better focused support and culturally affirming resources that account for multidimensional social locations. 19 Having a more nuanced understanding of how health inequities persist for Black people with IDD requires research teams to historicize and consider the intersections and entanglements of difference and social inequality, healthcare contexts, power relations, and the ways minoritized people resist contradictory categorizations of disability. 19-21 Therefore, failure to elucidate structural factors that perpetuate disability and disparities in health services research contributes to the on-going erasure of the Black disabled experience. 20, 22-23

In the following sections, we describe a Critical Participatory Action Research (CPAR) project and lessons learned from applying approaches that center and elevate the experiences of Black researcher partners with IDD, their care partners, and occupational therapy (OT) practitioners toward an anti-racist and anti-ableist pathway to healthcare. CPAR has many benefits including that it centers research partners' lived experiences, concerns, and beliefs on how to manage or improve the challenges they and others face.²⁴⁻²⁵ Its democratic approach to

knowledge production positions historically marginalized research partners as co-researchers, and thus, co-producers of the research.²⁴⁻²⁵ The literature points to the chronic marginalization of people with IDD and their care partners in research processes^{20,26}; in this project, we draw on the diverse strengths of academic, community, and provider partners by engaging in dialogue to compare, contrast, and problematize different and similar points of view.²⁴

Summary of the Project

Disrupting the Cycle, the moniker for the project discussed in this paper, offers new insights to address current gaps in health services research by seeking to understand the structural factors that impact healthcare access and utilization for Black people with IDD while enabling the development of enhanced, consumer-provider informed pathways to health. This manuscript reflects research activities completed between academic and community partners with IDD and their families in Aim 1, and academic partners, community partners with IDD and their care partners, and service providers in Aim 2. Those aims were to (1) identify the contextual characteristics that influence access for each minoritized research partner with IDD, which impacts their individual health service use; and (2) map the individual characteristics, contextual characteristics, and health behaviors of minoritized research partners with IDD that influence equitable service use and access following processes outlined in the Andersen and Davidson's²⁷ Behavioral Model of Health Services Use.

This project was approved by the Office of Human Research Ethics and the Institutional Review Board at [name redacted for peer review].

Lessons learned provide insights about participatory research processes, contextual mechanisms and their impact on health, and the need for community-led patient driven solutions.

The Disrupting the Cycle Partnership

In 2012, [name redacted for peer review], the principal investigator for *Disrupting the Cycle*, began establishing relationships through volunteer opportunities with communities of people with IDD and their care partners while a doctoral student at the University of North Carolina at Chapel Hill. She also forged partnerships within the IDD community through her work as an occupational therapy practitioner providing therapeutic services across the state. It was through these experiences that [name redacted for peer review] observed how Black people with IDD and their families were largely missing from the service recipient pool, and consequently, had to create formal and informal social networks to ensure their children with IDD had access to habilitative and educational services.

After completing her doctoral and postdoctoral training, [name redacted for peer review] deemed it necessary to build a coalition between the groups with whom she had partnered as a clinician and university researcher that aimed to ameliorate the enduring intersectional challenges facing the IDD community in NC. Partnerships were cultivated between university researchers including doctoral students with lived and clinical experiences working with people with disabilities from minoritized backgrounds, self and family advocates, practitioners with experience working with people with IDD in community settings (including practitioners who are also care partners of adult children with IDD), and a legislator with lived experience as a care partner of a child with a developmental disability (see Table 1).

Several partners occupied multiple positions (e.g., being both a provider and a care partner) and determined for themselves which partner role perspective they wanted to occupy throughout the project while recognizing that they could not fully sever their intersectional positions. In this way, *Disrupting the Cycle* represents a self-proclaimed community with a range of experiences and expertise unified under their shared backgrounds with IDD. This community

was primarily fostered via accessible video conferencing (i.e., Zoom), identified in collaboration with partners, to meet their specific needs. Partners also emphasized that meetings had to be mutually beneficial including using the project as a platform to raise and address concerns facing their communities as immediate benefits in this work.

Research Design

The primary objective of *Disrupting the Cycle* is to gain a nuanced understanding of the structural factors (e.g., structural racism, ableism) that impact health services access and utilization for Black people with IDD. More specifically, the project employed CPAR as a methodological framework to address issues of power and equity at the intersections of race, gender, disability, and other social locations.²⁴⁻²⁵

Partner Engagement Processes

Disrupting the Cycle followed conventional methods used in CPAR including individual semi-structured interviews, focus group and roundtable discussions, as well as interactive activities that aimed to facilitate deeper discussion (e.g., timelines, health narratives, access mapping).^{24,25} Individual interviews were one to one and a half hours in length while each focus group convened for one and a half hours. All sessions were audio and video recorded, and transcribed verbatim.

Aim 1 activities. Academic partners conducted individual interviews and facilitated four focus groups with community partners (i.e., people with IDD and their care partners) during the first phase of the project. Interviews were used to help community partners construct their health timeline by recalling and reflecting on key moments within their IDD experiences at a self-selected starting point. Community partners then built upon timelines to construct narratives and actor tables that identified trends in access as well as the important people, places, institutions,

and other resources to their stories.^{27,28} These narratives culminated in mapping actors and experiences onto their physical communities. Mapping also promoted dialogue between community partners on key features of a geographic area including its infrastructure, resources used (e.g., who and what are accessed and not accessed), and how these features change according to political and municipal boundaries. Community partners also noted the irony of experiencing disparities in medical access and care while living in resource rich communities.

These methods also allowed for the additional time and flexibility partners with IDD required to participate in conversations through communication media appropriate to their needs and adapted research materials and activities into accessible formats. The open-ended process of engaging in group dialogue empowered community partners with IDD and their care partners to steer conversation by identifying and elaborating on what they considered relevant and important with only minimal structuring guidance by academic partners. This coalesced to form a collective understanding between community partners with IDD and their care partners regarding concerns and perspectives about health, healthcare access, and structural inequities informed by their lived experiences. Community partners determined that their collective concerns and perspectives be presented to provider partners at the start of their involvement. In this way, priorities in the agenda evolved so that Aim 1, under the directorship of community partners, directly influenced the activities and conversations of Aim 2.

Aim 2 activities. Focus groups for the second phase of the project expanded to include provider partners in addition to community partners with IDD, and their care partners. To complement these collective conversations, academic partners also conducted individual interviews with each provider partner. Individual interviews aimed to capture their experiences working with and advocating for Black people who have a primary diagnosis of IDD. Additional

questions sought to elucidate their perspectives on barriers to health equity, values and beliefs around service provision, and preliminary assessments of accessible services in their community. Discussion-based focus groups included roundtable discussions such as healthcare experiences as both consumer and provider, healthcare priorities for community and provider partners, development of a model of action to address these priorities, and critical reflections to address misunderstandings and build consensus on the action model.

On average, focus groups included 10 community and provider partners. Sessions were facilitated by [name redacted for peer review] to provide a loose structure for timing and adaptations as needed for partners with IDD; however, community and provider partners also led discussions by sharing insights until they personally reached saturation. Partners had the power to steer conversation, return to previous topics of discussion, and build upon and ask follow up questions of fellow partners as desired. These data collection strategies integrated practical, participatory, critical, and reflective principles in an iterative cycle of observing, reflecting, planning, and acting. Further, these strategies created the conditions for all partners to name and frame the contextual factors that cause harm, and develop forms of emancipatory action that meet the needs of Black people with IDD through collaborative learning and planning. 25,30

Data analyses. Academic partners convened with community and provider partners during a regularly scheduled meeting that included a structured presentation about qualitative analysis and the proposed analytic procedures for the project. While a lack of community partner participation is noted as a limitation in analysis and interpretation processes,³¹ community and provider partners determined that the initial inductive coding and code book development was not the best use of their time; therefore, thematic³² inductive, simultaneous coding of five transcripts were completed by hand by the academic partners. The transcripts and subsequent

codebook were then provided to the community and provider partners for peer debriefing and collaborative deductive thematic analysis³³ during two, in-person data analysis workshops.

Workshops were held in-person in two different locations to facilitate access as community and provider partners resided throughout NC. Six partners attended the first workshop (two community, one provider, and three academic partners) and eight partners attended the second workshop (three community, one provider, and four academic partners). The decision to meet in-person was a response to community and provider partners' desires to strengthen the community being formed over videoconferencing. As such, workshops were designed to 1) further partnership relations (e.g., through meals and general socialization) and 2) analyze transcript(s) from a previous focus group dedicated to discussing emerging themes of holistic health, identifying stakeholders in IDD service provision, and perceived barriers to these stakeholders' equitable engagement with the IDD community.

For the data analysis workshops, community and provider partners were each provided paper copies of one transcript and the developing codebook. Together, they moved sequentially through each segment of text, described the codes they applied, and discussed their rationale. During the workshop, two graduate assistants took notes in addition to participating in discussion. Each session was recorded and transcribed verbatim. Although these workshops were deductive in nature, community and provider partners, through their lived experiences, further developed and transformed the proposed codes to enrich understanding in fruitful and novel ways.

Following the workshops, the academic partners coded the remaining transcripts utilizing the modified codebook. A list of primary themes and subthemes generated from their analysis were forwarded to community and provider partners to review ahead of two previously

scheduled meetings (one in-person meeting and one virtual meeting). During those meetings, all partner groups conferred about the meanings of each theme and deliberated any differences in perspectives until reaching consensus. Additionally, all partner groups discussed implications for action and potential strategies (see section on Future Directions). Modifications were made based on this feedback, and a final list of themes was disseminated to all partners.

Lessons Learned

The CPAR process presented both benefits and challenges to working with Black adults with IDD and their care partners. Below we outlined challenges as well as strategies to work through points of tension.

Challenges and Strategies

Amid the triumphs of CPAR, there are also inherent challenges of which research partners identified three key areas of concern: (1) delayed and staggered recruitment and retention of research partners from the community of focus; (2) power-sharing and equitable engagement; and (3) inclusive dissemination.

Delayed and staggered recruitment. Gaining multiple and diverse perspectives often facilitates greater depth and theoretical development in CPAR,²⁴ but can also necessitate staggered recruitment to ensure a diversity of perspectives.²⁵ Further, research partners may not be able to sustain engagement in research due to needing to prioritize other facets of their lives.²⁴ This can, and did for us, make for greater challenges in the recruitment and retention of research partners who are healthcare providers.

Committed to having healthcare professionals' perspectives on IDD service gaps with particular attention to racialized service disparities, we opted to recruit providers at professional meetings and conferences (i.e., NC OT Association annual conference; NC IDD Summit). More

specifically, we adapted a conference presentation as an IRB approved arm of the research, which allowed for us to gather data and to recruit participants for continued involvement in the research project. The academic partners engaged two audiences: (1) a formal presentation of the research to 27 OT practitioners, and (2) an informal discussion about the research to 75 individuals representing direct support professionals, disability advocates, self-advocates, payers, and legislators. While this process addressed the issue of recruitment and retention of provider research partners, it also created new challenges for those research partners who joined the CPAR project approximately halfway through the process. Challenges included limited rapport with other partners, limited understanding of the CPAR process, and limited exposure to information shared and gathered up to their entry.

Multiple opportunities for new provider research partners to connect were offered (e.g., virtual and in-person 'meet and greet' at an academic research partner's home) and helped facilitate increased engagement with community research partners; however, the strategies used did not fully ameliorate aforementioned challenges. The academic partners helped mitigate these gaps by providing comprehensive summaries of the process with recorded PowerPoint presentations and "Partner Office Hours" to answer specific questions and concerns, as well as leveraging breakout groups during meetings to facilitate informal discussions to build community between the various research partner groups.

Power-sharing and equitable engagement. Methodologically, CPAR strives to keep power relations in check, which can be difficult at times due to tensions between institutional and community demands.²⁴⁻²⁵ As noted by a research partner, the historical norm is to "look to the professional" for expertise (Community Partner SC); whereas in CPAR, the experts are research participants synthesizing knowledge from their life experiences.²⁴⁻²⁵ However, flattening power

hierarchies to center the voices of research partners, does not erase socio-historical context. As one research partner aptly expressed, "When you're not used to power, you don't know how to apply power...how do you apply power you've never had experience with?" (Community Partner SC). Moreover, engaging in research where racialized and disabled people have been systematically excluded can be disconcerting for people with IDD and their care partners who may not have experience conducting research. It can feel akin to "taking an artist out of the studio and putting them into a scientific lab" (Community Partner SC).

Several strategies were employed to work through challenges as they arose. A primary strategy employed during all research encounters involved co-reflexivity—an intentional exercise to assess and reassess engagement processes in real time to identify issues (e.g., PowerPoint content may not be accessible to partners with IDD) and co-create solutions (e.g., including picture symbols on PowerPoint slides to explain important concepts). These "check-ins" helped to facilitate deeper communication and capacity for community partners to lead discussions. To alleviate scheduling demands so that all or most research partners were able to attend meetings, each meeting ended with a discussion on the best times to meet next. For those not in attendance, an email was sent out to get their feedback for preferred meeting times. When research partners were unable to attend group meetings, they were provided a recording of the meeting and plain language summaries, as well as the option to meet individually with [name redacted for peer review]. This enabled research participants to stay abreast of discussions and to contribute their thoughts and insights to the questions posed.

Mitigating historical power inequities in this project was a process that developed through peer support, taking time for collective reflection, and partner positionalities, which enabled rapport and trust to build within the research team. We found the intentional use of

Zoom for research meetings (e.g., soliciting input for agenda-setting, research partners coleading discussion, using plain language summaries and accessible web features) helped ensure that everyone's voice was heard and integrated into discussions. Research partners also took the lead on how much time was needed to talk through and reflect together across the entirety of the project, especially within focus groups and individual interviews. In the words of two research partners, "It was intimidating in the beginning [...but] not being rushed into making decisions helped us [research partners] feel confident and empowered to share" (Community Partner AJ), and "You know at first, I didn't think I would have much to contribute...the process helped me see I had a lot to contribute to the conversation" (Community Partner CoC).

Inclusive dissemination. While participatory and inclusive approaches are complementary in their pursuits to center and elevate the voices of people with IDD, it is at times difficult to implement consistent, community initiated and led²⁶ dissemination strategies beyond traditional research products that are also practical for their own activism.³⁴ Throughout the project, community and provider research partners' perspectives were elicited around which accessible dissemination avenues would be most helpful for their work. For example, one community partner had experience advocating for those with IDD via televised and radio broadcast, and this was explored as a potential strategy for Disrupting the Cycle. Although community and provider partners were not interested in this strategy, they did seek to share the project at a holistic health community event organized and executed by community research partners that was attended by 286 greater community members.

Ultimately, partners were most concerned about reaching professionals who encounter those with IDD in their work given their considerable influence on the community's lives. This concern trended dissemination towards traditionally academic products as all partners felt this

had the most potential to reach this desired audience. Consequently, this required intentional planning to develop inclusive workshops for research partners on analytic processes (e.g., coding and data interpretation), academic writing, and presenting to professional audiences. Research partners then had to commit additional time to attend these workshops. Beyond manuscript writing, [name redacted for peer review] also advocated for, and secured, community research partner involvement, travel, and compensation for invited opportunities including keynotes, conference presentations, podcast interviews, and book chapters. Some of these activities have occurred (i.e., keynote, conference presentations, podcast interview) while others have been scheduled (i.e., book chapter) at the time of this manuscript's writing. Finally, community and provider research partners have expressed interest in generating a resource portfolio for providers in future iterations of *Disrupting the Cycle* funding phases.

To generate written products of the project, all partners in *Disrupting the Cycle* were invited to participate in two workshops to (1) learn more about publishing processes and manuscript preparation and (2) develop a detailed outline of this manuscript. Prior to indicating intent to participate in the manuscript, interested partners engaged in a discussion to elicit prior knowledge of academic writing. This discussion also included authorship criteria (including roles and responsibilities), a process overview of academic writing, tentative outline for the manuscript, and next steps. Those who were interested in writing self-selected which manuscript sections they wanted to make specific contributions. Together all partners established a writing schedule.

Based on interest, each section's authorship coincidentally equally consisted of one community partner, one provider partner, one academic partner, and [name redacted for peer review]. Partners expressed interest in and contributed to more than one section. Among each

manuscript section, partners established their own procedures for writing which often followed the lead and desires of community and provider research partners. This included all partners writing together in real-time, remotely on one's own time, collaborative dictation, and community and provider partners reviewing and providing feedback. Partners felt that the flexibility and mutual respect in decision-making around writing procedures made the process more accessible and engaging. It also allowed each partner to bring their own perspectives and expertise to produce an intersectional manuscript.

Any edits to others' writing beyond simple grammatical edits were first made as suggestions, followed by dialogue around the suggested change, and ending with mutual agreement. In this way, no partner possessed the power to outrightly remove or edit another's work. Writing check-ins were conducted after one month over email, then again after month two via Zoom meetings. Once all sections were fleshed out, all partners provided written and verbal feedback over the entire manuscript. After integrating that feedback, partners convened for a final meeting to review the completed manuscript together to discuss remaining edits prior to submitting it for consideration for publication.

Concerning inclusive strategies for partner participation in keynotes, conference presentations, and podcast interviews, [name redacted for peer review] facilitated planning sessions between event organizers and *Disrupting the Cycle* partners four to six weeks in advance to co-create discussion points, prioritizing those identified by community and provider partners. After these sessions, [name redacted for peer review] and the participating research partners scheduled meetings to flesh out ideas, develop visual aids, and determine which discussion points each partner would lead. Once that was determined, the participating research partners co-created scripts and practiced delivering their scripts to each other. Partners who were

not comfortable with public speaking recorded and edited videos or drafted vignettes to share during the presentation. Providing ample time, space, and flexibility to engage preferred communication methods supported the conditions conducive for research partners to show up fully as themselves.

Strengths of the partnership. In CPAR studies, there are often multiple actionable outcomes that move beyond the intended or initial goals of the research²⁴; and in regard to *Disrupting the Cycle*, community and provider partners were empowered to produce and share knowledge within and outside of the research context by transferring knowledge and skills from the project to other interactions with families and providers. This included, but was not limited to, coordinating a community fair to share resources to assist families with diverse healthcare needs; accepting invitations to speak on academic panels; interrogating discriminatory practices by physicians; participating in advocacy activities to improve community-based services for people with IDD; and joining community groups with missions to support health equity work.

Future Directions

Research activities for Aim 3 of *Disrupting the Cycle* are in progress. More specifically, academic, community, and provider partners are co-creating a conceptual model that encapsulates strategies identified in the data to improve service access and delivery in clinical and community settings for Black people with IDD from an anti-racist and anti-ableist lens. The model will be disseminated through traditional (e.g., peer-reviewed publication, conferences, and university press releases) and non-traditional/emergent (e.g., infographics for social media, visual abstracts, thematic hub) research outputs. Academic partners continue to meet quarterly with community and provider partners to coordinate dissemination activities of their work to date, as well as strategies to pilot action plans that address providers in the clinic and community

in their respective communities. Additionally, *Disrupting the Cycle* partners have identified and submitted one grant and a Letter of Intent to support the development of an anti-racist provider intervention at state and regional levels.

Conclusion

The overarching goal of this partnership process was to address inequities in health service access and use for Black people with IDD and their care partners. However, additional research that aims to ameliorate the structural mediators of health service access and use for Black people with IDD and their care partners is needed. CPAR has the potential to provide a more nuanced understanding of the ways structural determinants impact the healthcare experiences of this population. While lessons learned from *Disrupting the Cycle* point to several strengths of the CPAR process, it also highlighted challenges inherent to recruitment and retention of research partners from the community of focus, power-sharing and equitable engagement, and implementing inclusive dissemination strategies. Strategies employed to mitigate these challenges included creating opportunities for community and provider partners to cultivate relationships and build capacity to develop their own actions plans outside of the research project, engaging in co-reflexivity to assess and reassess engagement processes during research activities, and implementing inclusive strategies for partners to participate in academic and non-academic dissemination endeavors.

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Table 1. Research Partner Demographics

Partner	Partnership Role	Age	Self-Identified Race	Self-Identified Gender
DB	Community Partner, Adult with IDD	29	Black	Woman
KC	Community Partner, Adult with IDD	27	Black	Woman
OC	Community Partner, Adult with IDD	23	Black	Woman
VR	Community Partner, Adult with IDD	28	Black	Woman
AJ	Community Partner, Care Partner/Advocate	56	Black	Woman
CoC	Community Partner, Care Partner/Advocate	50	Black	Woman
SC	Community Partner, Care Partner/Advocate	65	Black	Woman
TH	Community Partner, Care Partner /Advocate	41	Black	Woman
ChC	Provider Partner, Occupational Therapist	28	White	Woman
CI	Provider Partner, Occupational Therapist	52	Black	Man
JL	Provider Partner, Occupational Therapist	39	Black	Man
СН	Provider Partner, Occupational Therapy Assistant	25	Black	Man
TJ	Provider Partner, Occupational Therapy Assistant	32	Black	Man
LP	Provider Partner, Advocacy and Service Organization Representative	62	White	Woman
ZH	Provider Partner, Legislative Representative	44	Black	Man
KJ	Academic Partner, Principal Investigator	40	Black	Woman

BP	Academic Partner,	43	White	Woman
	Graduate Assistant			
KP	Academic Partner, Graduate Assistant	32	Black	Woman
SM	Academic Partner,	24	White	Man
	Graduate Assistant			

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