A community-based approach to longitudinal language research with racially & ethnically

minoritized autistic young adults: Lessons learned and new directions

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1   **Abstract**

2   **Purpose:** Language and autism research each typically exclude racially and ethnically

3   minoritized (REM) autistic individuals. In addition, in the case of autistic individuals with

4   language impairment, investigators often approach caregivers to discuss research participation,

5   rather than autistic individuals themselves. This gap limits the ecological validity of language

6   research in autism. To address this gap, this clinical focus article describes strategies for

7   engaging REM autistic young adults with language impairment using lessons learned from five

8   years of longitudinal research with this population. This approach involved an ongoing

9   community partnership, as well as participatory partnerships with REM autistic individuals and

10   community stakeholders, developed through "slow science."

11   **Conclusion:** The approach yielded excellent retention of participants over five years and led to

12   co-development of research projects aimed at priorities described by REM autistic individuals

13   and their families, including understanding self-determination, social determinants of health, and

14   language variability in autistic REM with language impairment. Findings support the utility of

15   community-based methods with autistic REM young adults with language impairment, with key

16   take-aways for diversifying research while replicating, extending, and building theory.

17

18   **A community-based approach to longitudinal language research with racially & ethnically**

19   **minoritized autistic young adults: Lessons learned and new directions**

20   Though autism research infrequently reports participant ethnicity (Pierce et al., 2014),

21   such research largely excludes racially and ethnically minoritized individuals (REM), who

22   constitute the global majority (Durkin et al., 2015; Rivera-Figueroa et al., 2022; Roux et al.,

23   2015; Steinbrenner et al., 2022; West et al., 2016). Thus, the experiences of autistic REM have

24   been insufficiently represented in the development of diagnostic criteria, assessments, and

25   policies that impact their lives (Buchanan & Wiklund, 2020; National Institutes for Health,

26   2021). Autism researchers, including self-advocates, have called for removing barriers to

27   participation in research by REM and use of community-based approaches (George et al., 2014;

28   Jones & Mandell, 2020; Maye et al., 2021).

29   Community-based approaches are congruent with broader arguments for "slow science,"

30   or the gradual development of ecologically valid research that promotes reproducibility and

31   development of theory, as well as diversity among researchers and participants (Frith, 2020;

32   Leite & Diele-Viegas, 2021). However, even with community-based approaches, research with

33   REM autistic individuals tends to engage parents and not autistic individuals themselves (DuBay

34   et al., 2018; Ratto et al., 2017; Zamora et al., 2016). These approaches are insufficient for fully

35   understanding the language abilities and experiences of REM autistic individuals varying in

36   language skills and engagement strategies for longitudinal research (Gerhardt & Lainer, 2011;

37   Kuo et al., 2018; Shattuck et al., 2018; Teague et al., 2018; Winter et al., 2018). This clinical

38   focus article provides an illustrative example of a community-based approach to engage REM

39   autistic adolescents and young adults in longitudinal language research.

40   **Systematic Exclusion from Research**

41   The exclusion of autistic REM from research reflects larger sociocultural forces in the

42   research ecosystem (Girolamo et al., 2022b). Following intersectionality theory, REM may have

43   multiple intersecting identities, such as disability and being a minoritized individual, that are

44   each tied to experiences of marginalization and give rise to multiple marginalization that is

45   nuanced, rather than purely additive (Crenshaw, 1989, 1991). Dis/ability Studies and Critical

46   Race theory (DisCrit) centers race and dis/ability as mutually reinforcing social constructs that

47   reflect the reactions of others to individual differences versus individual differences themselves

48   (Annamma et al., 2013, 2018). Though these theories arose from legal and education studies,

49   respectively, they are applicable to clinical research.

50   Researchers work in an ecosystem that relies on convenience sampling to collect and

51   publish data as quickly and as cheaply as possible in order to meet promotion and tenure

52   guidelines, as well as funding agency expectations (Frith, 2020; Leite & Diele-Viegas, 2021;

53   Wendler et al., 2005). These institutional barriers come at a cost to minoritized individuals.

54   Clinical researchers make assumptions about who is a "good" research participant likely to

55   complete study activities or follow complex instructions; these perceptions may serve to exclude

56   autistic REM prior to recruitment (Joseph & Dohan, 2009). Extending the work of Joseph and

57   Dohan (2009), a "good" research participant is one who taxes the research process the least in

58   terms of time and resources. In general, this might mean a participant who has scheduling

59   flexibility, independent means of transportation, and access to reliable internet if data collection

60   is remote. In autism research, a "good" research participant might also mean one who has the

61   ability to use reliable speech and complete standardized protocols. In effect, both convenience

62   sampling and assumptions about the "ideal" research participants can thus contribute to

63   inequitable participation of autistic REM.

64   Importantly, research design conveys certain values and expectations to participants

65   (DuBay et al., 2018; Lewis Jr & Oyserman, 2016). We note some of the barriers that researchers

66   are responsible for perpetuating, drawing on evidence from research with REM and autistic

67   individuals, respectively, and noting the dearth of evidence on autistic REM. Given that

68   researchers may not know how to better recruit and work with diverse versus primarily white

69   participants (Ellis et al., 2021), we also offer strategies.

70   ***Research Sites and Scheduling***

71   One component of research design involves *when* a study takes place; research done only

72   during bankers' hours may conflict with caregiving, work, or other commitments (Brannon et al.,

73   2013; George et al., 2014). Research may also take place at locations that are less accessible to

74   REM communities (Brannon et al., 2013). For example, a single parent of a REM autistic young

75   adult expressed to the first author that she could not participate in a different university study to

76   access speech-language services for her child, because the research took place during working

77   hours and would require over one hour of travel on public transportation each way. Sociocultural

78   norms can also influence accessibility. Conducting research in an unfamiliar environment with

79   unfamiliar sociocultural norms, such as in a primarily white academic environment, may place

80   an undue burden on autistic REM and their families (Girolamo et al., 2020).

81   Fortunately, there are multiple strategies researchers can implement to remove logistical

82   barriers. One such strategy is locating research sites proximally to the neighborhoods of REM

83   autistic individuals and their families (Gowen et al., 2019; Ratto et al., 2017) In some cases,

84   investing in mobile data collection vehicles can enhance accessibility, such as the University of

85   Connecticut's mobile research and outreach unit that contains EEG and eye-tracking devices. If

86   research absolutely cannot take place in community settings, researchers might consider

87   providing transportation, establishing primary or satellite research sites near locations where

88   participants receive other services (e.g., clinics, community centers), flexible scheduling that

89   allows participants to choose among multiple opportunities and various modalities for

90   completing research activities (Brannon et al., 2013; El-Khorazaty et al., 2007; Ratto et al.,

91   2017). Last, regardless of where research takes place, compensating participants immediately

92   upon completion at an appropriate amount serves to mitigate the time and financial cost

93   participants incur in completing research activities (versus some other life activity) (El-

94   Khorazaty et al., 2007; George et al., 2014; Gowen et al., 2019).

95   *Trust and Community Partnership*

96   A third component of research design entails developing trust and rapport with

97   autistic REM. Researchers should make the effort to establish themselves as a trusted presence in

98   REM communities (Erves et al., 2017), with particular considerations for barriers at the

99   intersection of race and disability (Annamma et al., 2013). For instance, a qualitative study of

100   intermediaries during recruitment revealed that researchers often failed to meet with adults with

101   intellectual disability prior to enrollment or to ensure research activities were acceptable to

102   individuals with intellectual disability (Nicholson et al., 2013). Similarly, a narrative review of

103   assent procedures in behavior-analytic articles (a discipline adjacent to communication sciences

104   and disorders) found that 84% of 226 written reports provided no or minimal detail of assent

105   procedures for autistic individuals and individuals with developmental disorders (Morris et al.,

106   2021). One possibility is that participant agency is overlooked in research with autistic

107   individuals, particularly if researchers perceive autistic individuals to have limited preference by

108   nature of being ineligible to legally provide informed consent.

109   Insufficient trust and community partnership from the beginning of research can have

110   cascading effects that exacerbate experiences of marginalization. A meta-analysis of retention

111   strategies in longitudinal studies (Teague et al., 2018) and qualitative studies of Black adults'

112   views on research and underserved populations' research priorities (Erves et al., 2017; Freimuth

113   et al., 2007), respectively, found minoritized participants commonly believed that clinical

114   research only benefits white people, researchers are dishonest about their research aims, and

115   research staff lack cultural humility. In autism research, Black and Hispanic/Latine families with

116   autistic children report distrust of research as a factor in their decision to not participate (Ratto et

117   al., 2017; Shaia et al., 2020). Some of this distrust may arise from a history of research abuses of

118   the Black community, such as in the case of Henrietta Lacks or Tuskegee airmen (Katz et al.,

119   2006; Skloot, 2017). Some of this distrust may also arise from systematic exclusion of REM

120   from the research community.

121   Engaging autistic REM in research may involve building a community partnership and

122   learning about what engagement should look like for each participant; thus, it is not about

123   implementing a universal community-based strategy, but about . Importantly, though attending to

124   positionality (i.e., where one stands in relation to dynamics of power and privilege) is critical,

125   building community ties may be more important than racial and ethnic concordance for

126   developing trust and rapport with REM communities (El-Khorazaty et al., 2007; Kennedy et al.,

127   2010; Mindlis et al., 2020; Yancey et al., 2006). One way to achieve trust and rapport is by

128   partnering with community leaders or organizations (Erves et al., 2017; Kennedy et al., 2010;

129   Yancey et al., 2006; Zamora et al., 2016). This entails researchers developing a known presence

130   in communities (Erves et al., 2017), treating participants as equals (Kennedy et al., 2010; Lewis

131   Jr & Oyserman, 2016), and letting communities set the tone for interaction norms (e.g., letting

132   communities decide how they want researchers to interact with them) (Brannon et al., 2013).

133   Community partnership may also include developing advisory boards to advise researchers on

134   study activities or identify community priorities (Brannon et al., 2013; Erves et al., 2017; Haack

135   et al., 2014; Ratto et al., 2017). Personalized recruitment may be especially effective for

136   developing trust with individuals with dis/abilities (Lennox et al., 2005). Other individual

137   strategies that complement community partnership are rolling recruitment, where potential

138   participants can learn about the study and decide later whether to enroll (El-Khorazaty et al.,

139   2007), and dynamic consent, where participants can review their consent over the course of the

140   study (Budin-Ljøsne et al., 2017). In all, these strategies entail centering participants by showing

141   humility and *transparency*.

142   ***Communication Practices***

143   Communication practices may also convey to REM they are welcome or unwelcome in

144   research. Researchers may fail to maintain consistent contact with REM participants, or to follow

145   through with promised emails, resulting in loss of contact (El-Khorazaty et al., 2007). Implicit

146   cues may also send the message that REM participants are unwelcome. Researchers may fail to

147   use the preferred communication modality of REM participants (Erves et al., 2017), including

148   those with autistic family members (Gowen et al., 2019). For instance, Latine families of autistic

149   children report dissatisfaction with therapists who failed to listen and who spoke to one caregiver

150   rather than including the extended family (DuBay et al., 2018). Similarly, Black and

151   Hispanic/Latine adults (Erves et al., 2017), as well as individuals with intellectual disabilities

152   (Nicholson et al., 2013), report that researchers insufficiently explain study activities, with the

153   latter also reporting researchers ignore them in communications. Researchers may fail to use

154   accessible language (Kripalani et al., 2021), share research opportunities with REM (Erves et al.,

155   2017; George et al., 2014), convey the relevance of research to participants, or ensure

156   participants understand their rights (Brannon et al., 2013; Freimuth et al., 2001). These issues all

157   arise from communicative practices of researchers.

158   Creating effective communication involves cultural responsivity. One strategy is simply

159   to stay in contact throughout research on a regular basis (e.g., weekly or monthly), following up

160   personally, and communicating at the convenience of participants (Brannon et al., 2013; El-

161   Khorazaty et al., 2007; Nicholson et al., 2011; Yancey et al., 2006; Zamora et al., 2016). Other

162   ways to be culturally responsive to REM families of autistic children is by respecting family

163   perceptions about their child and following their communicative norms (e.g., speaking to and

164   facing the entire family versus just one caregiver) (Ratto et al., 2017; Zamora et al., 2016). In

165   addition, addressing autistic individuals themselves is critical to ensure they are interested in

166   participating in research regardless of whether or not their caregiver is the one providing

167   informed consent (Nicholson et al., 2013). Responsive communication could also entail the use

168   of appropriate language register and translation of study materials (Erves et al., 2017; Haack et

169   al., 2014; Kennedy et al., 2010; Nicholson et al., 2011; Ratto et al., 2017), as well as use of

170   dynamic informed consent and assent (Brannon et al., 2013; George et al., 2014; Gowen et al.,

171   2019). In all, researchers have many opportunities to proactively mitigate communication

172   barriers, thereby increasing the accessibility and inclusivity of language research. Together with

173   other barriers and strategies in research design, there is sufficient evidence for implementing

174   these strategies in research with autistic REM.

175   **Illustrative Research Project Example**

176   We developed a community-based approach from 2015 onward, drawing from prior

177   findings on effective research practices for REM, individuals with dis/abilities, and REM

178   families of autistic children, as well as our own research with autistic individuals and REM

179   varying in developmental profiles. The aim of the broader research project was to characterize

180   the language abilities and transition to adulthood of autistic REM with language impairment

181   (Girolamo & Rice, 2022; Girolamo et al., 2020). This entailed partnering with a community

182   organization serving primarily Black and Hispanic/Latine autistic individuals with LI, their

183   families, and community stakeholders to carry out five years of longitudinal research from 2018

184   to 2022 and to develop new directions for research; see Figure 1. This process led to the

185   recruitment of 18 participants, 14 of whom were Black and 4 of whom were Hispanic/Latine.

186   **Developing Trust and Rapport Through Community Partnership**

187   The first author approached a community organization serving primarily REM autistic

188   individuals to partner with them in research. Importantly, the first author obtained an initial

189   meeting through connections from the REM autism community and established a connection by

190   identifying as a former practitioner (and not an "ivory tower" researcher) with personal ties to

191   REM individuals with developmental disabilities. Entering the community by being *in*

192   *community* and showing humility by expressly stating that organizational leadership and staff

193   were experts in their work (versus implying or believing that a research degree conferred

194   expertise on the lives of the autistic REM they served) facilitated building rapport. Most

195   individuals at this organization were Black and/or Hispanic/Latine, with under 10% qualifying as

196   dual language learners. From 2015 to 2018, the first author met multiple times with

197   organizational leadership and staff to discuss study aims and the logistics of study activities. First

198   meetings involved introductions, discussing mutual interests pertaining to outcomes for autistic

199   individuals, and building rapport. A priority for the organization was ensuring that outsiders, like

200   the first author, understood the work of the organization. Developing trust involved leaving

201   space for the organization to tell the first author who they were and who the individuals they

202   served were, as well as by letting the organization decide when there was sufficient trust (i.e., the

203   organization brought up conducting research). Later meetings involved broad study aims and

204   working out the logistics of recruitment in a way that minimized disruption to organizational

205   programming. It was equally important to be flexible, as the organizational programming could

206   change at a moment's notice. In all, these steps, which took place over three years, supported

207   developing a community partnership and led to agreement to begin recruitment in 2018.

208   **Contacting Potential Participants for Initial Recruitment**

209   Per agreement with the organization to minimize disruption to their programming,

210   recruitment entailed distributing and collecting consent-to-contact forms and conducting research

211   off-site in community locations outside of programming hours. At the start of the study in 2018,

212   the first author traveled to the organization, distributed consent-to-contact forms to about 80

213   autistic adolescents and young adults and provided a brief explanation of the study in jargon-free

214   language. The organization did not provide contact information, and staff members did not have

215   the burden of distributing or collecting forms. All study materials were in General American

216   English at the average literacy level of adults in the community (i.e., 4th-grade reading level).

217   Potential participants did not have to decide about participation immediately. Rather, if

218   individuals were interested, they could take forms home and discuss with their families before

219   returning the form to school or contacting the first author. On the form and in contacting the first

220   author, participants and their families could share how and when they wanted the first author to

221   communicate with them (e.g., times during weekdays or weekends), including their preferred

222   modality (e.g., email, text, or phone) and accessibility needs. These visits to distribute and collect

223   consent-to-contact forms took place early in the morning or later in the afternoon to minimize

224   disruption, with several rescheduled visits due to changes in organizational scheduling or

225   inclement weather. Distributing and collecting these forms over three visits led to the return of

226   10 forms, with later check-ins leading to an additional 3 forms.

227   **Providing Personalized Consultation to Potential Participants and Their Families**

228   The first author contacted potential participants and their caregivers to provide a

229   personalized consultation about the study using their preferred communication modality and at

230   their preferred time. The author did not assume any prior research experience or knowledge of

231   research studies, as concepts like confidentiality and privacy have specific meanings that people

232   outside of research do not know (Girolamo et al., 2022a). Rather, the author provided a jargon-

233   free study overview, including detailed explanations of consent, assent, and participant rights.

234   Second, the first author sometimes spoke to not only participants and their caregivers, but also to

235   whoever they felt was a necessary part of their decision-making process (e.g., some requested the

236   author speak to extended family members and siblings). Throughout consultation, the author

237   encouraged potential participants to ask questions prior to scheduling a time to obtain informed

238   consent and assent. Example questions that participants and caregivers asked pertained to exactly

239   what participation in the study would entail, the duration of study activities, and how findings

240   would be used to increase the advocacy base for autistic REM. The first author successfully

241   reached and provided consultation to 11 of 13 (85%) potential participants who had returned a

242   form or contacted the author, all of whom indicated interest in participating. In subsequent years,

243   spontaneous participant referrals led to providing consultation to an additional five participants.

244   **Obtaining Informed Consent and Assent in a Dynamic Process**

245   The first author implemented a dynamic and interactive informed consent and assent

246   process. When research took place in person, this meant traveling to each participant and their

247   caregiver at a time and place convenient to them in their communities. Participants could select

248   places or tell the first author to provide options within walking distance from their homes. The

249   intention was to allow participants to choose a place that felt accessible to them. The first author

250   sent reminders of meeting times by text or phone, and participants could reschedule at any time.

251   Meetings took place evenings or weekends in community settings (e.g., libraries). The first

252   author explained the informed consent and assent forms line by line using jargon-free language.

253   Using graduated forms adapted from TalkBank (n.d.), participants and caregivers opted what to

254   share of their data and how to share their data (e.g., could elect to share de-identified data or

255   recordings). Participants and caregivers completed checks for understanding and were

256   encouraged to ask questions before providing assent and informed consent. In addition, the first

257   author provided them with copies of the forms and reviewed this information at subsequent

258   timepoints. If a participant provided consent upon their first time completing study activities,

259   they reviewed this information before assessment each year and received reminders that they

260   could stop being in the study at any time. This process led to 18 of 18 participants providing

261   informed consent and assent.

262   **Carrying Out Research Activities in Accessible Settings**

263   As with all parts of the study, participants and their caregivers could reschedule at any

264   time. The first author answered questions and concerns on research activities during and after the

265   visit to increase participants' and caregivers' comfort. For example, if a caregiver or participant

266   asked about the purpose of a receptive vocabulary measure, the first author debriefed with them

267   either during or after the task, whichever minimized disruption to the participant. Similarly, if

268   caregivers or participants expressed anxiety about their child's or their own performance, the

269   author listened to their concerns, offered to share a score summary (per institutional review

270   board approval), and reiterated that the only expectation was they try the activities out to the best

271   of their abilities and interests. Upon completion, participants and their caregivers immediately

272   received compensation.

273   To date, all 18 participants who started assessment have completed one or more

274   timepoints of data assessment. The first two timepoints of assessment involved an hourlong

275   protocol of age-referenced language and cognitive assessments, with 10 participants assessed at

276   Time 1 and 7 participants at Time 2. At Time 2, two participants who had completed assessment

277   at Time 1 were unavailable for assessment but interested in the study. At Time 3, which

278   coincided with the onset of the COVID-19 pandemic in spring 2020, 11 participants completed

279   assessment. This necessitated a re-envisioning of the approach for an online modality.

280   Specifically, online assessment meant leaving space for participants and their caregivers to elect

281   how they were going to participate in the study. For example, one participant who had moved

282   during the pandemic introduced the author to their siblings and extended family members, who

283   each asked questions about the study. This process may have enhanced participation in

284   subsequent timepoints of data collection, which were also online due to the pandemic, and

285   referral of others to this study. By the fifth year of data collection in 2022, five participants

286   participated in their first time-point of data collection, four in three timepoints of data collection,

287   two in four timepoints of data collection, and seven participants in their fifth timepoint of data

288   collection.

289   **Following Up with Participants and Community Partners**

290   Following study visits, the first author remained in contact with participants by sending

291   study communications including a "thank you" card after each session, birthday cards, seasonal

292   greeting cards (including those specific to holidays that participants celebrated), and general

293   greeting cards. These written communications served a dual purpose. First, they ensured that

294   contact information was correct, in that participants were invited to provide updated contact

295   information. Second, these cards provided a friendly, low-stakes way of keeping the study in

296   participants' minds. Further, the first author checked in with participants and their caregivers

297   during the beginning of the COVID-19 pandemic by phone or text. At the same time, the first

298   author also kept in touch by in-person visits, mail, and email with the community organization to

299   check in and revise the partnership as needed. For example, change in the structure of the

300   organization necessitated streamlining communication to minimize burden to the organization.

301   This strategy led to staying in contact with 16 of 18 participants over the course of

302   five years. One participant had contact information that changed, and one stopped responding

303   during the pandemic. However, participants and caregivers typically showed enthusiasm in ways

304   that indicated comfort with the study. One participant sent an unprompted email about their

305   interest in participating in the study and life updates. Caregivers and participants also sent text

306   messages and cards to the first author during the holidays, sharing updates (e.g., experiences with

307   trying to access services). One caregiver shared that although their child typically liked being

308   alone and would disengage from social interactions, the participant reported enjoying the study

309   visits. Others asked detailed questions about the life of the first author (e.g., whether the first

310   author celebrated a given holiday), so that they could be culturally sensitive.

311   **Summary**

312   Though the sample is small, this community approach led to rich interactions with

313   participants and their families. In particular, investing targeted time and effort to partner with a

314   community organization and allowing participants to elect when and where to complete study

315   activities with transparency throughout the process facilitated sustained trust and rapport. This

316   approach is one illustrative example of what a community-based approach might look like in

317   language research when working with autistic REM. In this present case, this approach laid

318   ground for development of ecologically valid research questions and inclusive research methods,

319   congruent with "slow science" (Frith, 2020; Leite & Diele-Viegas, 2021).

320   **New Directions and Lessons Learned**

321   Initially, the research from the community-based approach focused only on individual

322   differences (Girolamo & Rice, 2022), which is consistent with autism research (Anderson et al.,

323   2018). However, REM autistic and neurodivergent individuals, as well as their family members

324   (e.g., Black parents of young minimally verbal autistic children, who are not part of the

325   neurodiversity self-advocacy space) were highly interested in research with their communities.

326   We describe some of the newly developed areas of research, which are being conducted with

327   new partnerships, as well as lessons learned from this ongoing work; see Figure 1. All activities

328   take place at the time, convenience, and preferred modality of community partners.

329   **New Directions in Research: Social-Ecological Factors**

330   One new line of research arising from the community-based approach aims to holistically

331   characterize social determinants of health in autistic REM with language impairment. A clear

332   finding from the initial study was that assessing only individual difference measures was

333   insufficient for understanding the transition to adulthood in this population. Interactions with

334   participants and their families revealed that environmental influences impacted their responses

335   on individual difference measures, such as a parent sharing that a participant would never

336   socialize on their own independently due to racism and ableism in society, which meant their

337   scores on an adaptive behavior measure were lower due to social-ecological effects versus

338   individual differences. Therefore, we addressed environmental factors in the following ways.

339   In attending a community event for REM in the health professions, the first two authors

340   met an REM neurodivergent practitioner. They discussed common interests, as each worked with

341   autistic REM. Over several years, regularly inviting the practitioner to engage with them on the

342   practitioner's terms led to the joint decision to build a larger research team to pursue

343   investigation examining the role of environmental factors in outcomes that included person-

344   centered measures. This directly supported the practitioner's goal of addressing interests relevant

345   to themselves and their community, as well as the interests of all authors. Research team

346   members included other REM practitioners, autistic and neurodivergent individuals, parents of

347   autistic and neurodivergent children, and established researchers and students who wanted to

348   learn about participatory approaches in clinical research; this included all co-authors of this

349   report. The team set ground rules for inclusion of all perspectives, with the expectation that the

350   most under-heard voices would be centered in this work.

351   Setting ground rules entailed inviting team members to join the project in a graduated

352   procedure: (a) identifying potential team members and meeting with them individually on their

353   terms to talk about conducting research (e.g., at an off-campus location following their

354   preference for modality, whether in-person, by Zoom, phone, or email), (b) introducing team

355   members to one another, (c) assessing potential for developing trust and rapport with more

356   dominant team members (e.g., white academic researchers) among more minoritized team

357   members (e.g., autistic REM), (d) obtaining agreement from each team member that the team

358   members who research tends to systematically exclude would have priority in terms of meeting

359   agendas, speaking time, and project development, (e) working with more minoritized members

360   to identify ways to remove the burden of conducting research (e.g., going over project

361   development in individual meetings versus sending a written document for feedback; Teague et

362   al., 2018), and (f) checking in on a monthly basis to gauge the sense of comfort of minoritized

363   team members with the project and fellow team members. Importantly, setting ground rules

364   meant implementing a "zero tolerance" policy for discrimination and disrespect. If at any point a

365   team member does not feel respected or safe, then research will halt until a resolution acceptable

366   to them is reached.

367   With these rules in place, the team worked collaboratively to identify measures that

368   aimed to recognize the agency of autistic REM with language impairment and their families.

369   This led to identifying validated person-centered measures that were relevant to the experiences

370   of autistic REM, and importantly, that autistic REM from the initial study had shared in years of

371   communication with the first author. Consequently, the research team developed a novel

372   interview support structure to enhance the accessibility in terms of language and cultural

373   sensitivity of the Self-Determination Inventory (Shogren & Wehmeyer, 2017). In an iterative

374   process, research team members identified potential issues with accessibility at the item-level,

375   generating a scaffolded interview support structure to allow multiple opportunities for

376   questioning and discussion prior to responding to an item. In this ongoing partnership, autistic

377   and neurodivergent REM (who are not participants) are invited to serve as research partners,

378   with their investment in the project recognized by authorships and roles on funding applications.

379   The objective of this partnership was to share the experiences of autistic REM in a way that did

380   not aim solely to pathologize. However, we suggest that fully valuing community partners

381   involves including community partners in leadership roles (Nicholson et al., 2013).

382   **New Partnerships with Leaders of Geographic and Virtual Communities**

383   In addition to new research, we expanded our partnerships to include community leaders

384   of geographic regions and of virtual communities. Sharing our research to multiple constituents

385   at community events opened new pathways to developing additional community partnerships.

386   First, the Black practitioner from the social-ecological factors project coordinated a meeting

387   between the authors and a local community leader with decades of experience in the public

388   schools. The community leader wanted access to resources and supports for Black parents of

389   minimally verbal autistic students, as well as support in applying for grants to obtain resources

390   (e.g., augmentative and alternative communication devices) for these students. The authors

391   provided resources on the terms of the community leader, who then offered to partner in

392   research. Similarly, the practitioner connected the authors with an REM parent of autistic

393   children who is a leader of a large virtual community, which includes a parent support group and

394   programming for parents of autistic children. Again, the authors introduced themselves over time

395   and provided resources on the terms of parent.

396   We note that while centering the priorities of autistic individuals themselves is critical, in

397   these scenarios, partnering with community leaders and parents was important. This is because

398   autistic REM, such as a minimally verbal five-year-old autistic child, are extremely unlikely to

399   independently attend a community talk or enter the self-advocacy space (in which autistic REM

400   with language impairment like participants in our research are scarce). Thus, we trusted that

401   family members of autistic REM who knew them best would be able to support autistic REM in

402   communicating what their interest was in research. As for partnering with autistic individuals

403   themselves, speaking about the intersection of race and dis/ability in the health professions led to

404   connecting with an REM autistic self-advocate who co-founded a "for us, by us" autistic self-

405   advocacy organization. As with the first community leader, partnership aligned to mutual

406   interests and areas of expertise. The long-term aim is to implement sustainable partnerships

407   where researcher and community partners are equally valued, as reflected in grants, publications,

408   and bring mutual benefit to communities (Ellis et al., 2021).

409   **Lessons Learned**

410   Overall, the initial study and subsequent research with new community partners, provide

411   an example of how one might engage autistic REM in research. Though we recognize that

412   researchers face institutional barriers, amid systemic barriers to engaging autistic REM in

413   research, we offer some lessons learned and a flowchart of possible questions researchers might

414   use to develop community-based approaches; see Figure 2.

415   *Community Partnership*

416   Overall, researchers must have appropriate expectations for what is feasible in

417   community-based approaches (Frith, 2020; Leite & Diele-Viegas, 2021). Clearly, this research

418   was more labor intensive than convenience sampling and yielded a sample size that is smaller

419   than many researchers may need to satisfy funders. However, regular contact with this sample

420   led to rich information and research that is ecologically valid to not just scientists, but to autistic

421   REM themselves, in terms of how autistic REM see themselves (Buchanan & Wiklund, 2020)

422   and their lived experiences (George et al., 2014; Gowen et al., 2019; Haack et al., 2014).

423   One question researchers can ask themselves is whether they truly partner with autistic

424   REM on a study from conception through dissemination. If so, then researchers should consider

425   whether the norms of the project (e.g., communication frequency and modality) reflect the

426   preferences of autistic REM. If not, then researchers should consider whether the study engages

427   autistic REM and jointly identify areas for fuller partnership, following the goals and priorities of

428   autistic REM. If researchers do not engage autistic REM, they could engage autistic individuals

429   who are white and consider how missing the perspective of autistic REM on the research team

430   affects their research. Similarly, researchers can also ask themselves how not engaging autistic

431   individuals impacts their science.

432   ***Be a Good Research Partner***

433   A second, broad lesson learned is the importance of being a good research partner. This

434   involves ensuring that the spirit of community partnership, which depends on cultural humility

435   (Erves et al., 2017; Freimuth et al., 2001; George et al., 2014), continues throughout a research

436   study, from dynamic consent to research activities and dissemination.

437   **Dynamic Consent.** If scientists invest the appropriate time and energy to get to know

438   their target participants, communication preferences, and accessibility profiles, scientists can

439   implement dynamic consent and assent. In this process, it is critical to consider how to know

440   autistic REM will show understanding of research jargon pertaining to consent, assent, and

441   participant rights. Relevant questions are whether there are consent and assent materials

442   accessible at an individual level, as well as time to ask questions. Researchers should be

443   proactively mindful of cultural norms. For instance, if a participant and their family are of a

444   culture unlikely to ask questions, regardless of level of understanding, *a priori* preparing

445   questions pertaining to what consent is and is not could be useful. Next, a researcher should

446   consider whether a participant shows understanding *after* implementing consent materials and

447   processes accessible to them. If not, then researchers should revise materials and procedures,

448   ideally with autistic REM community partners.

449   **Research Activities.** A second area for being a good research partner is research

450   activities. Researchers must consider whether activities align to the preferences and priorities of

451   autistic REM as much as possible, while also considering the requirements of the research. For

452   instance, some participants indicated they largely preferred meeting in person during the

453   COVID-19 pandemic. Clearly, that was not possible. In such cases, researchers should consider

454   whether there are "good" reasons for not following participant preferences and transparently

455   explain that reasoning to participants. In our case, transparency allowed for reaching consensus

456   on the modality of research activities. However, if, for example, a participant prefers to complete

457   research activities at a place accessible to them and there is no reason for research activities to

458   take place at a fixed location, then researchers should revise activities in the spirit of inclusivity.

459   **Dissemination.** A third area that is critical for community partnership is ensuring

460   research findings are impactful for autistic REM themselves. To start, researchers must ask

461   whether the community wants research findings to be broadly disseminated, and if so, what their

462   priorities are for dissemination. If not, researchers might ask if the community wants some type

463   of advocacy from findings and then advocate following the terms of the community. In our case,

464   autistic REM on the research team, community stakeholders, participants, and their families felt

465   strongly about the experiences, abilities, and perspectives of people like them having a seat at the

466   table. This meant sharing not just the empirical findings, but also *advocating* for implementation

467   of community-based strategies as scientifically rigorous and *translating* this appreciation into

468   engagement strategies. For example, knowing that one participant was proud of being in the

469   study and a role model for their nieces, the first author scheduled time at each assessment session

470   to speak with their nieces with family permission (though they were not part of research). In

471   addition, it was important for the authors to be highly responsive to requests from community

472   partners for resources or assistance to support autistic REM. An example of this was finding

473   resources for autistic REM to support their young adulthood goals, as well as co-developing

474   research projects with autistic REM. These methods likely supported retention, consistent with

475   prior work with families of autistic REM (Zamora et al., 2016).

476   *Mitigate Biases*

477   Of course, an underlying lesson from this research is that all researchers in

478   communication sciences and disorders have the responsibility of co-constructing an accurate

479   narrative of REM engagement in research and practice with REM and other stakeholders in their

480   lives. That is, researchers must de-construct the narrative that REM are less willing than white

481   counterparts to participate in research through actions (Wendler et al., 2005). Scientists should

482   critically examine how their own judgments of who is a "good" research participant can lead to

483   research design that serves to exclude autistic REM (Joseph & Dohan, 2009; Zamora et al.,

484   2016). Acting upon this bias could mean working with community partners to build inclusive

485   research methods that leverage community strengths, such as conducting health research that

486   supports community priorities on the weekend at community events like farmers markets (Lewis

487   Jr & Oyserman, 2016).

488   **Conclusion**

489   　　　In developing a multi-year community approach to longitudinal language research with

490   autistic REM with language impairment when approaching autistic individuals themselves, we

491   generated new research directions and partnerships. Working with community partners

492   underlined the importance of identifying barriers preventing autistic REM with language

493   impairment from achieving their goals, as well as of developing person-centered measures that

494   yield valid results by being culturally sensitive to autistic REM. The new directions for research

495   from this approach has strong implications for building meaningful research. It is our hope that

496   the methods and lessons learned are useful to others endeavoring to do this type of research.

497   **Acknowledgements**

502   **Data Sharing Statement**

503   All data are reported and available in the article.

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695   6

696   Figure Legend

697   Figure 1. Overview of an illustrative community-based approach

698   *Note*. Blue and green indicate individual projects. Orange indicates ongoing activities, with

699   annual assessment per participant.

700   Figure 2. A flowchart for thinking through community-based approaches.
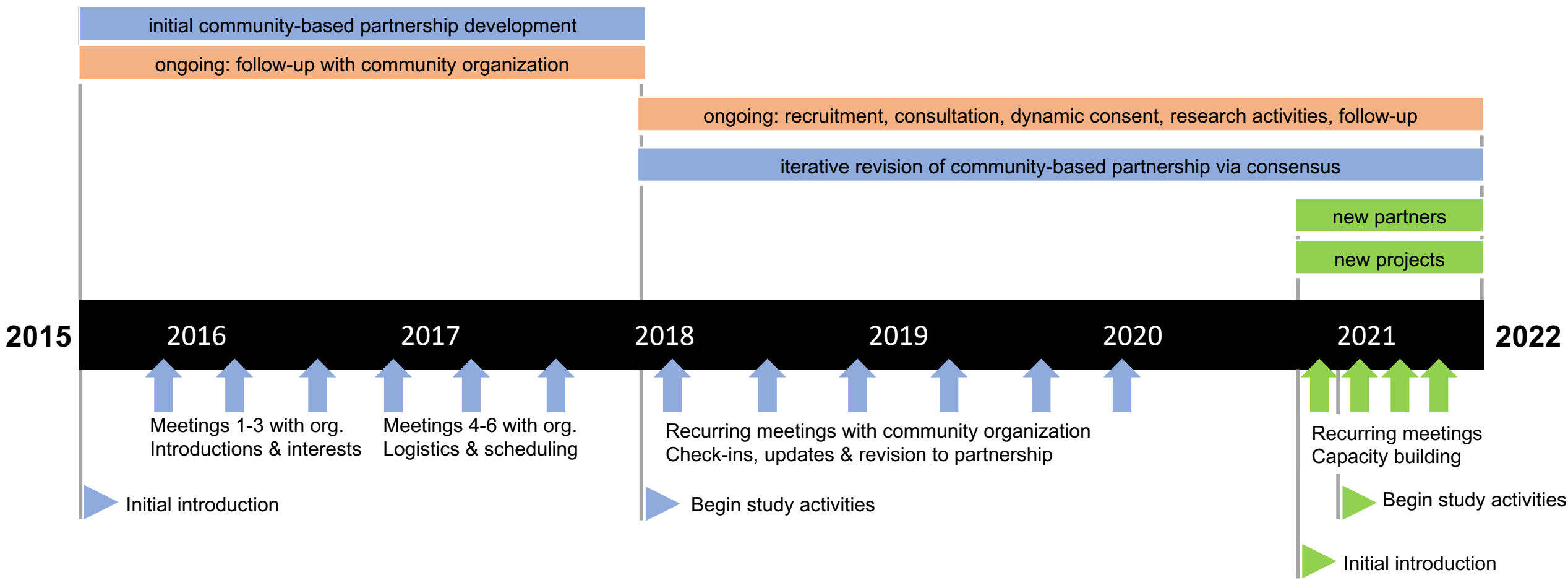
Development of community-based approaches

Community partnership

Does the study partner with autistic REM throughout?

Consider if norms reflect autistic REM preferences

Does the study engage autistic REM?

Identify areas for fuller partnership

Does the study engage autistic individuals?

Consider how positionality impacts research

Consider how absence impacts research

Dynamic consent

Does the participant show understanding of research jargon & participant rights?

Obtain informed consent & assent

Are there accessible materials & time to ask questions?

Obtain informed consent & assent

Is there understanding after using accessible materials?

Obtain informed consent & assent

Revise materials & procedures for accessibility

Research activities

Do activities align to participants' preferences as much as possible given the nature of research?

Proceed with research

Are there viable reasons why not?

Explain, consensus before proceeding

Revise activities to align with preferences

Dissemination

Does the community want research findings to be disseminated?

Check diss. aligns to community priorities

Does the community want advocacy from findings?

Advocate on community terms

Identify other pathways for sharing research