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# Toward Integration of Life Course Intervention and Youth Participatory Action Research

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We provide an overview of diverse forms of youth participation, with a focus on youth participatory action research (YPAR) and its synergies with life course intervention research to promote healthier development for young people and across the life span. We analyze why YPAR matters for research, practice, and policies related to the systems and settings in which young people develop. We also illustrate how young people perform YPAR work to improve the developmental responsiveness and equity of school and health systems, including descriptions of an innovative youth-led health center in Rwanda and a long-standing and evolving integration of YPAR into public high schools in the United States. We then briefly consider the adult capacities needed to do this work well, given that YPAR challenges typical youth-adult power relationships and broader assumptions about who can generate expert knowledge. We consider the alignment and potential challenges for integration of life course intervention research as well as YPAR and next steps for research and practice at this intersection.

abstract

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Young people around the globe have experienced deep social and academic disruptions as a result of the COVID-19 pandemic, which has elevated deeply rooted social, economic, and racial inequities, widening already pervasive gaps in education, health, and socioeconomic status. How will these losses and stressors affect the health and well-being of young people now and across their life spans? The authors of the Life Course Health Development (LCHD) framework,<sup>1-6</sup> which extends classic biopsychosocial<sup>7</sup> and socioecological frameworks,<sup>8-11</sup> emphasize how social and biological contexts interact with the characteristics of individuals, especially during sensitive periods, to shape human development and health across the life span. Development is shaped by interactions with immediate settings ("microsystems," eg, families, schools, neighborhoods), the linkages among microsystems ("mesosystems"), and broad cultural, political, and economic systems ("macrosystems").<sup>8</sup> The importance of how humans adapt to the resources, stressors, and constraints in families, schools, and neighborhood microsystems, as well as larger economic, health, and political systems, is also highlighted in LCHD.

There is much that cannot be controlled in the larger economic, political, and health contexts that shape human development. At the same time, the identification and enactment of opportunities for meaningful agency and purpose are critical for all, but particularly for adolescents who are uniquely poised in the developmental window of defining identities and heartfelt passions and with the potential to shape their developmental pathways within the constraints of their contexts.<sup>12–14</sup> In the United States and globally, we have seen a recent

upsurge in collective activism by young people on pressing issues such as climate change, gun violence, and systemic racism. Young people are gaining and using power to try to change the contexts that shape their development.

The more visible resurgence of youth activism in expressing political "voice" is occurring in the case of a quieter, but long-standing movement over the past 2 decades to strengthen the meaningful participation of youth in settings and systems that affect their development and health, including kindergarten to 12th-grade (K-12) education,<sup>15,16</sup> nonprofit and afterschool programming,<sup>17</sup> health services and systems,<sup>18</sup> child welfare,<sup>19</sup> community/neighborhood development, and municipal governance.<sup>20</sup> This shift toward youth participation and decisionmaking has rationales that vary from international movements based in the United Nations Rights of the Child<sup>21</sup> that assert ethical claims for participation in policies and decisions that affect them<sup>22</sup> to effectiveness-oriented claims that youth participation in research, intervention, and evaluation efforts will yield better designs, measures, processes, and outcomes.23,24

There are multiple forms of youth participation, such as youth organizing, youth boards, and youth participatory action research (YPAR). In YPAR, youth train in research methods to study and improve conditions in settings (eg, school, neighborhood, health system) relevant to their lives.<sup>25-32</sup> YPAR entails a cycle of research, action, and evaluation in which youth advocate for changes informed by their research findings. YPAR is the most research-intensive form of youth participation, with the most attention in the published literature.

LCHD and the principles of life course intervention research (LCIR) are important lenses for understanding how YPAR and other forms of youth participation can shape life course development. In turn, YPAR is a promising and relevant approach for informing and strengthening LCIR because of its focus on empowering young people to respond to the stressors they experience and improve the systems that undermine their healthy development and those of their peers, families, and communities. In this article, we provide an overview of YPAR and its relationship to other forms of research and youth participation, making a case for why these approaches matter for LCIR, practice, and policies related to the systems and settings in which young people develop. We illustrate how young people perform YPAR work to improve the developmental responsiveness and equity of school and health systems, and we consider the alignment as well as the potential challenges for integration of LCIR and YPAR and the next steps for research and practice at this intersection.

#### WHAT IS YPAR?

As a youth-focused form of participatory action research, also known as community-based participatory research, YPAR is not a research method but a research approach in which decision-making is driven by and in partnership with those affected by a given issue. Participatory research has long and diverse historical roots within and across fields, such as public health, social work, education, community psychology, and international development, with varying emphases on social justice versus effectiveness. The values and context are important to acknowledge here because they inform the potential implications and challenges for integration of

LCIR and pediatrics in general. The explicitly liberatory and social justice streams of YPAR draw theoretical grounding in the Global Southern traditions of participatory research, popular education,<sup>33,34</sup> and grassroots development in Latin America and South Asia. The Northern tradition of stakeholder inquiry for organizational improvement and intervention draws on Kurt Lewin's early action research in social psychology on the importance of worker expertise and buy-in for organizational change and effectiveness.<sup>35</sup> Data-based inquiry is valued in both participatory streams to inform action by insiders with lived experience who are viewed as experts on the issues under study but vary in the relative focus on systematic change and equity.

#### **Process**

Typically, in partnership with adults, YPAR groups identify research priorities and questions to investigate. They select a relevant design and methods depending on their questions and scope (eg, surveys, interviews, observations, photovoice, mapping). Youth systematically collect and analyze data, identify relevant stakeholders, and create data-based presentations and products to share and advocate for change. Youth have engaged in YPAR to address a wide range of health-related and health equity issues, such as gender-based violence, bullying, unequal access to healthy food and physical activity opportunities, concentrated tobacco and liquor store density in lowincome neighborhoods of color,<sup>30,36,37</sup> and exposure to hormone-disrupting chemicals in pesticides and personal care products.<sup>38,39</sup>

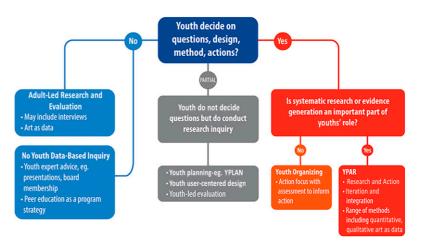
#### **Focus and Outcomes**

Two recent systematic reviews of the YPAR literature<sup>40,41</sup> in the

United States revealed major growth in the field, with most of the 3700 studies in the literature published since 2009. In a detailed review of 67 studies that examined the impact of YPAR, the authors found that 50% focused on educational domains, 40% on social inequalities. 32% on health, and 25% on violence and safety. Most studies reported on individual health outcomes, including substance use, healthy food access, physical activity, and asthma. A review that focused on setting-level changes, rather than on individual outcomes, revealed that all policy outcomes reported were in the health domain.<sup>41</sup> As we discuss later, youth engaged in YPAR to target health outcomes that they care about address the adverse person-environment mismatches and stressors that can drive health inequities emphasized in the LCIR model.

#### YPAR AND OTHER FORMS OF YOUTH PARTICIPATION

Researchers have analyzed diverse forms of youth participation of likely relevance to LCIR, such as YPAR, youth boards, youth organizing, human-centered design, participatory arts, and participatory planning.<sup>23,42,43</sup> In this comparative overview, we aim to (1) promote a shared framework to guide potential integration with LCIR and (2) advance understanding of the ways in which LCIR could potentially lead researchers to enact meaningful youth participation strategies to improve health practices and policies. As noted in Fig 1, a key distinction between YPAR and other participatory approaches is that youth decide on questions, design, and/or methods. In adult-led research and evaluation, youth may be consulted (eg, focus groups to guide an intervention or evaluation) or provide various forms of quantitative or qualitative data (eg, interviews, poetry) but do not have a role in determining research questions, designs, methods, or interpretation. The yes side of the decision tree in Fig 1 includes partial or full power for determining phases of the research process. Under partial are approaches such as youth planning, evaluation, and human-centered design in which youth typically do not generate the research questions but bring their expertise to meaningfully shape data-based inquiry. On the right side, are YPAR and youth organizing. These approaches share features of



#### FIGURE 1

Mapping youth participation approaches. (Reprinted with permission from Ozer EJ, Abraczinskas M, Duarte C, et al. Youth participatory approaches and health equity: conceptualization and integrative review. *Am J Community Psychol.* 2020;66[3–4]:271). young people generally driving the inquiry and action but differ in that YPAR has a strong emphasis on data-based inquiry and generation of knowledge (to inform action), whereas youth organizing is typically much more heavily focused on activism to change a specific policy or practice. Youth organizers may gather information to inform campaigns, but systematic evidence generation is not a focus. As examples related to LCHD, youth researchers might conduct a county health needs assessment and use the data generated to inform revisions to local health practices, whereas youth organizers might advocate at a state house or organize a protest about a mental health issue that affects their lives.

#### LCIR AND YPAR: INTERSECTIONS POINTS AND IMPLICATIONS

YPAR is aligned with key principles and characteristics of LCIR.<sup>44</sup> In the next sections, we outline 4 key areas for fruitful integration, potentially strengthening the alignment of other interventions and systems with these principles.

#### 1. YPAR as Intervention on Stressors and Systems That Underlie Health Inequities

Decades of developmental research have revealed the importance of context, including systems, on longterm youth developmental outcomes.<sup>45</sup> Positive developmental settings promote physical and emotional safety, relationships, social norms, expectations for behavior, and developmentally appropriate structures and rules.<sup>46</sup> A focus of YPAR is understanding and addressing the kinds of adverse person-environment mismatches, socially structured pathways, and toxic stressors that underlie and exacerbate health inequities highlighted in the LCHD framework.<sup>4,47</sup> Specifically, the young people engage with the YPAR process in a socioecological analysis of the root causes of the problem to be studied and changed, moving toward using a systems change lens and away from a focus on the individual.

YPAR and LCIR are aligned by their emphasis on the impact and influence of multiple ecological levels of youth and family functioning and well-being. YPAR and LCIR are complementary, however, in that the research focus of YPAR is explicitly on systems/ contexts to directly change them. In addition to macrosystem changes, YPAR has potential effects on interpersonal processes through strengthening of relationships and increasing understanding between youth and adults and building skills in communication. In a K-12 public school example in Stockton, California, student researchers identified that few students felt as though they had an adult who cared about them on campus. The teachers then spent time exploring why that might be; they then created opportunities for stronger connections, yielding stronger student connectedness scores in a subsequent assessment.48 Interpersonal connections are especially relevant to pediatric health care, as some inequities stem from mismatches in provider and patient understanding and stereotypes.<sup>49</sup> Researchers can integrate YPAR and other forms of youth participation with LCIR as a strategy to inform policy and make changes at multiple levels of pediatric health care. YPAR can be used to assist with tailoring structures, processes, and programs/services to meet the LCIR goal of optimizing the health development trajectories of youth and families while also addressing health care inequities.

Youth participation methods can contribute to the LCIR field to

reform inequitable conditions that create barriers to optimal health, such as the lack of focus on maternal and child health. despite evidence for its long-term importance.<sup>4</sup> Youth and families could take the lead on challenging systemic issues in health care through work on advisory boards, advocacy groups, or research teams to guide local action around health and health equity important to their local context. Youth participation processes can also contribute to a paradigm shift toward whole-person and lived experiences of health versus only conditions that can be identified objectively, as is the current focus in health care systems.<sup>4</sup> Youth participation processes may also lead to increased access to and retention in health care services, as these processes are well-suited to uncover implicit biases and other interpersonal and contextual dynamics that influence full and long-term engagement in health care settings.

#### 2. Integrating YPAR and LCIR for Creative Codesign to Improve Research and Intervention

Through YPAR, youth have opportunities to put into action key LCIR principles of the creative codesign of interventions and consultation with community members in the definition and measurement of outcomes. The fact that insider youth are performing the research potentially affords them key opportunities to provide insights on the contexts shaping their development. A strong case can be made for the potential gains in rigor, relevance, and reach afforded by participatory research (eg, see Balazs and Morello-Frosch<sup>50</sup> and Kaufman et al<sup>51</sup>). When youth (and their families, in some cases) perform research on issues that affect them and their communities. their insider knowledge can guide them to identify questions,

problems, and solutions that traditional research may miss. YPAR may especially enhance study validity for sensitive health-related topics, such as violence, sexual relationships, bullying, and sexual and reproductive health. Depending on their age, young people's experiences with peers and environments may be less controlled by parents or guardians, many of whom may not even know about these activities. Adolescents usually have more freedom to engage with ecological microsystems, such as media, neighborhoods, and peers, than do children. Many youths become independent and mobile through public transit or cars. Thus, YPAR can be an enhancement of LCIR because youth researchers bring insider knowledge of issues and solutions most salient to their developmental stage to relevant constructs, questions, methods, interpretation, and dissemination strategies, as well as potentially lead to creative solutions.<sup>52,53</sup> For example, in the summer of 2020, adult planners from the Boston Youth Resiliency & Recovery Collaborative used elements of YPAR to inform the development of a citywide intervention to support Boston youth and families affected by the opioid crisis and substance use. To inform the intervention, adult planners and the external evaluator worked with a team of youth ages 16 to 18 years who guided the development of a focus group protocol examining youth priorities for the initiative. Six focus groups were then facilitated by youth and adults, and the results were vetted by the team with additional groups of youth and the broader Boston Youth Resiliency & Recovery Collaborative coalition. In this case, youth contributions were critical for helping adults to understand drug use and its impact in the context of the pandemic, as

well as youth priorities related to intervention.

An increased focus on patient voice in health care has been seen in the past decade,<sup>54,55</sup> yet few models of youth engagement and leadership in health care delivery exist in the United States, whereas promising practices have been noted in Canada and Europe.<sup>56,57</sup> Researchers of youth engagement in health through advisory boards or councils<sup>56,57</sup> have reported positive outcomes and roles for youth and the community, as well as nuanced insights about mental health systems and access to care and health information.<sup>18</sup> Community participants in research design and data collection can contribute to a more nuanced understanding of patient experiences with health care delivery and the factors that shape health. Community participants in dissemination can ensure that findings and recommendations are aligned to community priorities. Moreover, engaging the community can ensure findings are not presented in a way that reinforces deficit-based stereotypes or otherwise problematizes and pathologies the community. YPAR processes can inform the development and adaptation of health interventions to make them more developmentally appropriate and culturally relevant.<sup>18</sup> Effect sizes in health interventions often decrease when moving from efficacy to effectiveness trials. It is especially difficult to maintain effectiveness with interventions focused on adolescents<sup>58</sup> and minoritized communities.<sup>59</sup> Addressing recruitment, retention, and fit issues through cocreating and/or adapting interventions using participatory methods can potentially help to maintain the strength of effects.<sup>59,60</sup> A systematic review found that when community-based participatory research strategies

were used in intervention trials, recruitment and retention of minoritized groups was high, and 89% of the studies revealed positive outcomes.<sup>61</sup> Interventions may not be as effective in communities if they fail to align with youth and family needs, values, resources, and interests. Specifically related to adolescents, interventions are less effective when adolescents perceive them as telling them what to do, undermining their sense of autonomy.<sup>62</sup>

An illustration of YPAR integration in a health intervention to enhance fit and impact occurred as part of a study by Abraczinskas and Zarrett.<sup>17</sup> The authors engaged students in YPAR to enhance systems-level impacts of a physical activity intervention focused on individual behavior change with middle school youth from disadvantaged, minoritized backgrounds. During their participation in a physical activity intervention, youth also participated in photovoice to highlight facilitators and barriers of physical activity, presenting their photos to afterschool and school leaders to show inequities in physical activity access. In one example, girls reported that they wanted to participate in physical activity (eg, dance) but did not have activities that matched their interests. On the basis of this identified need, afterschool staff integrated dance into ongoing programming. Physical activity increased pre- to postintervention,<sup>63</sup> and structural changes were implemented to meet youths' needs and interests long term.<sup>37,64</sup> Aligning interventions to better meet participants' needs can help to increase buy-in and engagement, and systems changes can promote the sustainability of positive outcomes and programming long term.

#### 3. YPAR as Intervention to Support Youth Development Over the Life Course: YPAR and Developmental Windows

Another important potential intersection of YPAR with LCIR is related to how YPAR can support the developmental opportunities and transitions for young people who participate, as well as support healthy development for those in the schools and communities that YPAR seeks to improve. YPAR processes aim to make settings and systems more developmentally supportive and responsive for all children and adolescents (especially minoritized and marginalized ones) and support the developmental tasks of adolescence. Through YPAR, opportunities are provided to build young people's sense of responsibility and need to contribute,<sup>65</sup> which can enhance their individual and collective sense of identity and purpose.<sup>66–70</sup> Early adolescence is a key inflection point for intervention experiences such as YPAR that can be used to capitalize on sensitivity to positive peer regard and provide opportunities for the development of heartfelt goals and positive passions.71,72 Furthermore, because adolescence entails increased malleability of selfconcepts and behaviors as youth engage in identity development in their environments,<sup>73</sup> youth who participate in health-related YPAR may value health and integrate that attitude into their developing identities.<sup>74,75</sup> Health-focused values that form in adolescence may solidify into health-promoting behaviors in adulthood.73-76

An LCHD/LCIR framing informs how we conceptualize YPAR as a life course intervention. YPAR most often engages adolescents, and adolescence is a sensitive period for the acquisition of capacities for later health,<sup>77</sup> with the continuation of physical activity into adulthood being one example. In addition to the importance of this sensitive period, LCHD theories can help to guide YPAR efforts that specifically focus on developing, improving, or evaluating prevention and intervention strategies to optimize health. Overall, YPAR can be a powerful developmental intervention for youth while also leading to research and systems change to improve the contexts in which youth grow and develop. As an LCIR approach, YPAR has the potential to lead to a more positive developmental cascade, influencing and improving multiple interacting systems cumulatively across development, where overall benefits may not be fully actualized until later in the developmental trajectory.<sup>37,78</sup>

#### 4. YPAR and LCIR: Strengthening Antiracist and Antiageist Lenses

An important stated value of LCIR<sup>44</sup> is an equity-focused, antiracist lens. Racism is endemic in US systems and embedded in policies and organizational practices.<sup>79</sup> YPAR is asset based, with researchers aiming to advance equity and is a promising approach to advancing antiracist practice in LCIR in that participants reject dominant narratives that associate knowledge production with whiteness and adulthood. YPAR participants instead seek to elevate young people's expertise and power as they grapple with the root causes of inequity, seeking to reimagine oppressive systems and to advance health and well-being through datadriven collective action. YPAR can thus serve as a form of resistance to structural racism.80

YPAR also brings an antiageist lens that situates young people as experts.<sup>81</sup> Society privileges the voices and views of adults as knowing best, and youth are typically not consulted in adult-designed policies and programs intended to shape the environments and wellbeing of young people. The participatory absence of young people as key stakeholders in policies, practices, investments, and other decision-making processes can lead to adult-prescribed interventions that do not adequately respond to the needs of young people. Through YPAR, young people have the opportunity to identify, describe, investigate, and address the social factors and context to which they are exposed. Evidence generated from YPAR can be used to contribute to the creation of more relevant and responsive health interventions.

Through YPAR, space is created for young people to exercise their agency to address social, racial, and economic inequities that directly affect their health and well-being. For example, participants in a YPAR project on adolescent coping strategies supported by the RYSE Center in Richmond, California, presented the concept of intersectionality<sup>82</sup> to help young people to explore and conceptualize how systems of oppression disproportionately affect individuals or communities across markers of race, class, gender identity, sexual orientation, and so forth.83 Participants in another YPAR project with the RYSE Center investigated air pollution inequities and incorporated a structural violence framework to aid young people in analyzing the clustering of environmental harms like the inequitable proportion of hazardous sites located in disadvantaged communities.<sup>84</sup> Both projects resulted in recommendations and health interventions that were directly informed by the lived experiences of young people.<sup>83,84</sup>

#### FUTURE OPPORTUNITIES AND CHALLENGES FOR THE INTEGRATION OF YPAR AND LCIR

Participatory research approaches with community stakeholders affected by the issue under study in

the role of scientific investigators and change agents, rather than as more passive providers of data or recipients of services, turn the traditional scholarship enterprise on its head by challenging assumptions about who is expert and who can create knowledge.<sup>27</sup> Further, YPAR challenges dominant assumptions about adolescents, particularly minoritized youth, by creating the conditions and opportunities for participants to develop skills and exercise agency over stressors and systems that impede their healthy development and that of their peers. YPAR, therefore, is intentionally disruptive to the status quo of power in the scientific enterprise and the health and educational systems in which young people develop. Simultaneously, YPAR is generative in that young people engage in evidence-based inquiry that can enhance their own development while improving "youth-serving" health and educational settings, such as schooling, to better serve them. These disruptive and generative qualities are exciting potential synergies with the vision for LCIR to fundamentally redesign our pediatric health care and other systems to focus on optimizing health rather than on acute needs.<sup>4</sup> Furthermore, because this redesign requires a nuanced understanding of the role and experience of dynamic microsystem and macrosystem effects on development, the insider expertise and interventions enabled by YPAR can be particularly fruitful for this novel revisioning of adolescent health and well-being. The iterative cycle of inquiry embodied in YPAR is also wellaligned with new movements in implementation science, such as the design experiment approach in education<sup>85</sup> and the engineeringbased iterative alternatives to randomized controlled trials (RCTs),

such as the multiphase optimization strategy.  $^{86}\,$ 

#### CAPACITY AND READINESS CHALLENGES

Potential challenges for the integration of YPAR into LCIR and pediatric health include insufficient capacity and resource commitments on the part of the organization or project to have "good enough" processes in which (1) youth are scaffolded and supported to have a positive and effective YPAR experience and (2) adults are sufficiently trained and prepared to value their input and be responsive and accountable to what the youth find. We are mindful that youth are not the only stakeholders in complex systems and organizations, and YPAR is one form of evidence that decision-makers will be considering; thus, being responsive and accountable does not mean blanket agreement with YPAR-based recommendations but, rather, the creation of the conditions for authentic consideration and response.

Over the past decade, principles, processes, and curricula to support high-quality training of adult facilitators and implementation of YPAR have been developed.<sup>31,87–93</sup> Beyond training the young people and adult advisors who participate, it is critical to assess the systems and organizations within which YPAR occurs. Participatory models challenge the norms of organizational cultures in which young people are expected to be subordinate to adults and in which professionalism, expertise, and knowledge are associated with adult status, position title, and whiteness.<sup>94–96</sup> Are there structures to support relevant youth input into decision-making? Are there resources to train and sustain YPAR partnerships over time versus a "one-off" that would be better

served by formative research with existing youth leadership groups? Or, in the case of a time-limited YPAR project, how can strategic analysis clarify how findings and recommendations will be considered with accountability? These questions go beyond the practical (eg, how to fairly compensate young people for their time) to adults being intentionally in relationship with young people. In YPAR, adults working in partnership with youth have an important role in grappling with and contesting power structures that impede relationship development. Thus, there is a need to be ready for the feelings of discomfort that may arise to avoid reactions of dominance or fragility, which may cause additional harm.

Another challenge for YPAR and LCIR integration relates to the structures of US health care systems, such as insurance reimbursement and structured workflow processes that push providers to be maximally efficient, potentially making participatory processes challenging within these settings. Previous participatory efforts led by families have been successful at challenging practices within the office structures themselves to be more inclusive (eg, changes to office environments, diversity trainings for front desk staff),<sup>51</sup> but making systemic change at the overarching health care structure level will be challenging. Furthermore, given medicine's favoring of RCTs, it is important to emphasize that participatory processes have been used with many research designs, including RCTs.

Future areas of research at the intersection of YPAR and LCIR include long-term follow-up studies of YPAR engagement to determine the impact of YPAR on development, if YPAR is more effective in some developmental windows versus others,<sup>72</sup> and if YPAR processes and

settings in which they occur can help to positively modify the developmental trajectories of minoritized youth. A strength as well as challenge is the varied epistemologies for YPAR; with diverse methods and actions, there are not shared priorities on outcomes to be measured or the value of longitudinal assessment. Furthermore, although our central focus has been on YPAR, we note that there are important examples of intergenerational YPAR in which families and their children work together, particularly among indigenous communities.<sup>97–99</sup> This approach may be a particularly fruitful direction for some areas of the LCIR field, especially those in which an intergenerational dialogue to frame the issues may be of particular value.

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#### **ABBREVIATIONS**

K-12: kindergarten to 12th grade LCHD: Life Course Health Development LCIR: life course intervention research RCT: randomized controlled trial SFUSD: San Francisco Unified School District YPAR: youth participatory action

research

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