The Collaborative HIV Prevention and Adolescent Mental Health Project (CHAMP) family-based HIV prevention Approach

ArvinBhana, PhD

Child, Youth, Family & Social Development Research Programme

HSRC

HSRC Human Sciences Research Council

Collaborators

- Mary McKay, PhD – Department of Psychiatry and Community Medicine, Mt Sinai School of Medicine, NY
- Carl Bell, MD – Department of Psychiatry, University of Illinois, Chicago and Community Mental Health Council
- Claude Mellins, PhD – HIV Center for Clinical and Behavioral Studies, NY State Psychiatric Institute & Columbia University, New York
- Inge Petersen, PhD, School of Psychology, University of KwaZulu-Natal, South Africa

Outline of Presentation

- Founding Principles
- Guiding Principles
- Core Implementation Principles
- Theoretical Standpoint
- Adaptation
- Programme Delivery
- Facilitator Roles
- CHAMP Refocus

HSRC
Human Sciences
Research Council

CHAMP: Founding Principles

- CHAMP was initiated on the basis that programs that appear to meet with the most success are:
  - Relatively comprehensive
  - Focused on practical problem solving skills in addition to the provision of information
  - and based upon basic research data from the targeted community
  - Context and culturally sensitive by partnering community stakeholders to shape, translate, and deliver the prevention/intervention work.

Madison, M., McKay, M., Paikoff, R., & Bell, C. (2000). Basic research and community collaboration: Necessary ingredients for the development of a family-based HIV prevention program. *AIDS Education and Prevention,* **2** (4) 281-297

Rotheram-Borus, M.J., Swendeman, D., & Chovnick, G. (2009). The past, present, and future of HIV prevention: Integrating behavioral, biomedical and structural intervention strategies for the next generation of HIV prevention. *Annu.Rev.Clin.Psychol, 5*, 143-167

CHAMPSA Guiding Principles

- Developmental model that proposes complex interplay between individual and family variables that promote health and inhibit very early sexual activity (i.e., prior to 14 years of age) for youth approaching adolescence in a high-risk context. (Paikoff, 1993, 1997)
- Development from childhood to adolescence involves change in cognitive (e.g., reasoning), social (e.g., relationships), affective (e.g., feelings about self, relationships, and society), and biological (e.g., puberty) factors
- Hence, tasks of parenting and of family life must change to accommodate adolescents' increasing independence and unsupervised time with peers. Families adaptation to changes are likely to influence child risk for HIV exposure and other health compromising behaviors (Paikoff & McKay, 1995)

Context of African Families

- Given dominant collectivist culture in Africa, where group norms and processes take precedence over individual decision-making (Airhihenbuwa & Collins, 2000), nature and expression of support requires critical consideration.
- Social support and social networks in relation to building protective family influences within the African socio-cultural context as well as the context of poverty needs need to be better understood

Airhihenbuwa, C.O. & Obregon, R (2000). A critical assessment of theories /models used in health communication for HIV/AIDS. *Journal of Health Communication, 5 (Supplement), pp. 5-15,*

Core Implementation Principles

- High levels of family involvement
- Facilitators exist in natural settings
- Materials are easy to use and accessible and available in user-friendly delivery formats, e.g., facilitator manuals, cartoon-based story line
- Providers have the capacity to implement programmes
- Targets multi-level outcomes
- Engages participants with highly interactive activities such as one-on-one, small group and community-level skill building and dialog

Albarracin, D., Gillette, J.C., Earl, A.N., Glasman, L.R., Durantini, M.R et al. (2005). A test of major assumptions about behavior change: a comprehensive look at the effects of passive and active HIV-prevention interventions since the beginning of the epidemic. *Psychol. Bull. 131*(6), 856-897.

Theoretical Standpoint

- Eco-developmental perspective
  - ***Intrapersonal Influences*** – to strengthen key personal influences such as parental self esteem and self-efficacy, communication and active monitoring skills in parents as well as parent and child HIV knowledge.
  - ***Interpersonal and community influences*** - to strengthen social networks and social support to create a more health enabling family and community context as well as health enhancing parental identities
  - ***Culture/Environment influences*** - to facilitate health enhancing attitudes towards parenting as well as HIV positive people through diffusion of innovation

Applying Field Principles

Field Principle	Activities to actualise people
Facilitate connectedness at various levels	Facilitate attachment of youth to caregivers and vice versa, youth to schools, caregivers to schools, neighbours and communities
Facilitate improvement of self-esteem	Improve individuals' sense of power (self-efficacy), uniqueness, provide models and connectedness
Development of social skills	Communication skills, parenting skills, refusal skills, negotiation skills, leadership and management skills
Provide access to evidence-based interventions	Using established evidence-based interventions to care for individuals, families and groups

Bell, C.C., Bhana, A., McKay, M.M., Petersen, I. (2007). A commentary on the Triadic Theory of Influence as a guide for adapting HIV prevention programs for new contexts and populations: The CHAMP-South Africa story. *Social Work in Mental Health*, *5*(3/4), 243-267.

Applying Field Principles

Field Principles	Activities to actualise people
Minimise trauma	Develop an individual's sense of self-efficacy; create a sense of safety, social networks, and social fabric
Re-establish the adult protective shield	Develop caregiver monitoring systems for youth and developing community systems that protect youth
Rebuild the village	Bring stakeholders together to agree upon a shared vision of developing social capital (social networks, relations, trust, and power either at city or neighborhood level) to create an interdependent network of people, functions and services designed to create interconnectedness between stakeholders, safety, security and synergy.

Adaptation Process

- CHAMP intervention in South Africa utilises Freireian principles of participatory adult education
- Behaviour change emerges from a process of critical reflection on one's own lived experience leading to the development of critical consciousness (Freire, 1970)
- Small group participatory experiential learning facilitates this process through iterative process of discussion and discovery successfully used in behaviour change programmes with youth (Campbell & MacPhail , 2002)

Programme Delivery

- All programme content delivered to family adults and children groups were interactive in own groups and then in dialog with each other
- Approach is supported by the finding that participating in a group setting is effective with urban populations participating in both prevention and treatment interventions (McKay, et al., 1998; Tolan & McKay, 1996)
- Meta analysis also shows small group and community-level skill building and dialog important to programme efficacy (Albarracin, et al., 2005)

CHAMPSA Family Program - Sessions

- Meeting 1: Parents' and Children's Rights and Responsibilities
- Meeting 2: Parenting Styles
- Meeting 3: Talking and Listening
- Meeting 4: Puberty
- Meeting 5: Hard to Tell Stuff
- Meeting 6: Identifying Risk
- Meeting 7: What is HIV/AIDS?
- Meeting 8: Dealing with Stigma
- Meeting 9: Surviving Loss and Bereavement
- Meeting 10: Support Networks

The AmaQhawe FAMILY PROJECT

OPEN-ENDED PARTICIPATORY CARTOON NARRATIVE

DISCUSSION OF SENSITIVE SUBJECTS

- Cartoons "contain" anxiety through providing distance from the issue

FACILITATES PARTICIPATORY PEDAGOGICAL METHODS TO PROMOTE EMPOWERMENT

- Participants' close narrative through discussion
- Facilitates the development of critical consciousness and health enhancing social practices

FACILITATION

Parents selected and trained to deliver program

TAKE HOME BOOKLETS

Assignments facilitate consolidation of material learned during sessions

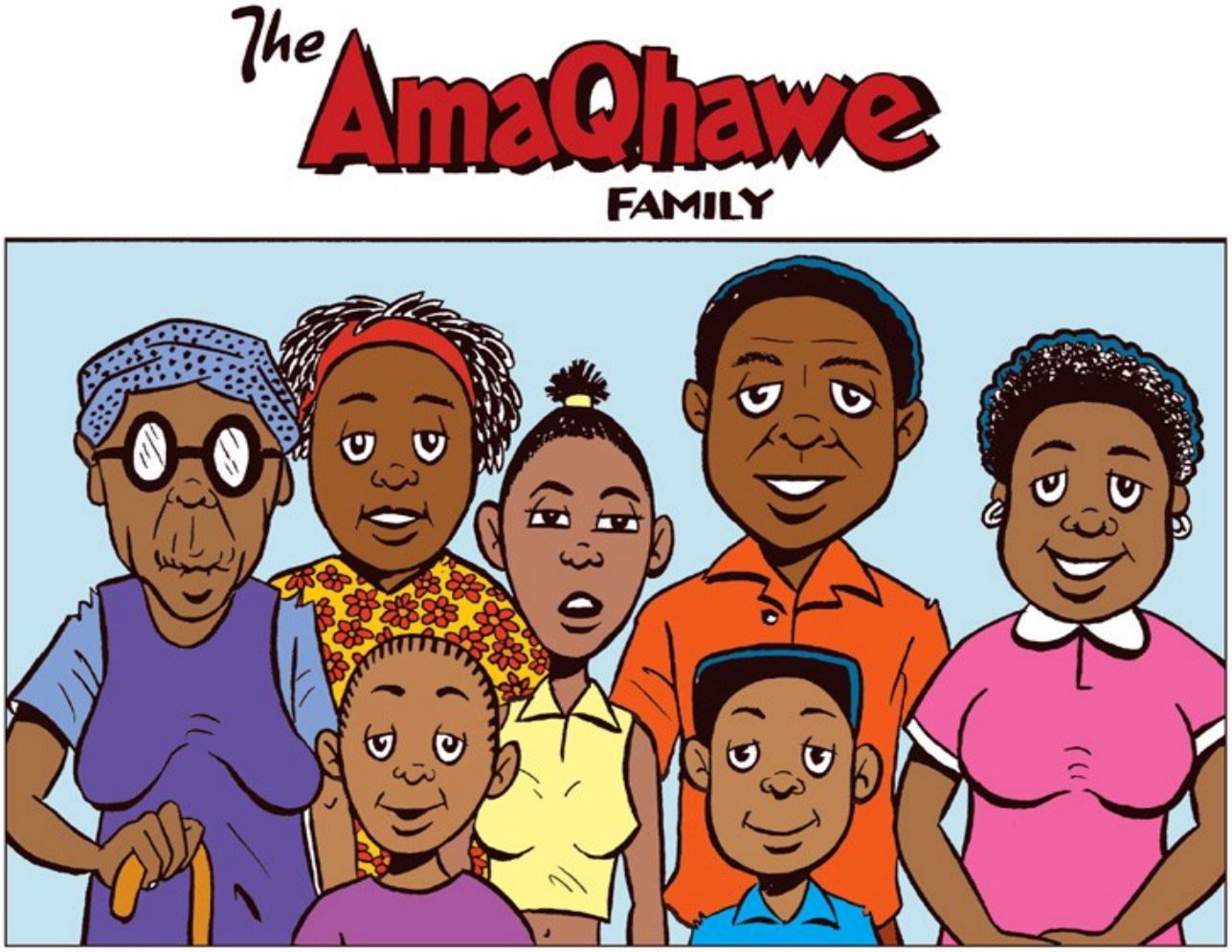
Facilitates diffusion of innovation through involvement of non-participating members especially fathers

Facilitated Critical Dialogue

- Process provided the dialogic space for the participants to reflect collectively about the issues raised in the narrative episodes
  - *"I think it's a way all stories are planned, all stories come to an end while you still want them to continue and they leave it to you to continue… You put yourself in the shoes of the people in the stories and think if you were them what would you do. I like the way stories end because it leaves us with a task to continue on our own"*

Petersen, I., Mason, A., Bhana, A., Bell, C.C., & McKay, M. (2006). Mediating social representations using targeted micro media in the form of a cartoon narrative in the context of HIV/AIDS: The *Amaqhawe Family Project(CHAMP)* in South Africa. *Journal of Health Psychology, 11*(2), 197-208.

THE CHARACTERS



The AmaQhawe FAMILY PROJECT
Session 1
CHAMP
THE CHEEKY SON
GOAL!
WELL DONE!
BBQ
CONTINUED ON BACK PAGE
The AmaQhawe FAMILY PROJECT
Session 2
THE TEMPTATION
ZZZZ
Session Two
The AmaQhawe FAMILY PROJECT
Session 5
HARD TO TELL STUFF
Later...
Session five

Facilitator Roles

- **Facilitator effectiveness enhanced because:**
  - Community-based family members trained by CHAMP staff recognised for their skills and knowledge as well as empathy with the families in the community
  - More effective model because facilitators came from the same communities (Crepaz et al 2006; Durantini et al 2006)
  - Facilitator and family group were similar with regard to ethnic, gender, age, behavioural and background characteristics (Crepaz et al. 2006)
  - A minimum of two facilitators ran each facilitated family group programmes (Copenhaver et al. 2006)

Social Support

- Social support viewed as important to family-based interventions because of collectivist ideas of support and the role of networked social relationships.
- *Social networks* can be seen as the web of social relationships that surround individuals.
- CHAMP assisted in re-establishing these networks to provide a source of support to each of the families

Intervention Effects-Scale Change Scores - Caregiver Data

Bell, C., Bhana, A., Petersen, I., McKay, M.M., Gibbons, R., Bannon, W., Amatya, A. (2008). Building protective factors to offset sexually risky behaviors among Black youth: A randomised control trial. *Journal of the National Medical Association, 100*(8), 936-944.	Estimate	Std Error	P Value	Effect Size
Social Networks Primary	1.5581	0.6068	< 0.0106	0.2653
Social Networks Secondary	2.8756	0.7549	< 0.0002	0.4531
Neighborhood disorganization	-1.1166	0.3688	< 0.0026	-0.3134
Neighborhood Social Control	1.7976	0.7845	< 0.0224	0.226

Intervention Effects-Scale Change Scores - Caregiver Data

Bell, C., Bhana, A., Petersen, I., McKay, M.M., Gibbons, R., Bannon, W., Amatya, A. (2008). Building protective factors to offset sexually risky behaviors among Black youth: A randomised control trial. Journal of the National Medical Association, 100(8), 936-944.	Estimate	Std Error	PValue	Effect Size
HIV transmission knowledge	0.9148	0.2131	< 0.0001	0.496
Less stigma toward HIV infected people	5.7192	0.8987	< 0.0001	0.698
Caregiver Involvement	-0.9059	04134	< 0.0289	0.2
Caregiver Communication Frequency	1.1437	0.6202	< 0.0657	0.24

Intervention Effects-Scale Change Scores - Child Data

Bell, C., Bhana, A., Petersen, I., McKay, M.M., Gibbons, R., Bannon, W., Amatya, A. (2008). Building protective factors to offset sexually risky behaviors among Black youth: A randomised control trial. Journal of the National Medical Association, 100(8), 936-944.	Estimate	Std Error	P Value	Effect Size
HIV transmission knowledge	0.82	0.27	< 0.0647	0.50
Less stigma toward HIV infected people	3.86	0.92	< 0.0045	0.70

Champ Refocus on HIV+ Adolescents (CHAMP+)

- Increasing no. of HIV+ older children & adolescents in sub-Saharan Africa
  - Untreated slow progressors as a result of vertical post-natal infection (Ferrand, et al., 2009)
  - Increase in PMTCT (73% in SA in 2006) will slow overall burden of infection in children but not reduce post-natal vertical infection through breastfeeding (Ferrand, et al., 2009)
  - Scaling up of ART will also increase number of fast progressors entering adolescence (Ferrand, et al., 2009)

Ferrand, R.A., Corbett, E.L., Wood, R. et al. (2009). AIDS among older children and adolescents in Southern Africa: projecting the time course and magnitude of the epidemic. *AIDS*, 23 (15), 2039-2046.

HIV Positive Youth

- Adolescence particularly vulnerable period for HIV+ youth in relation to:
  - mental health problems (Mellins, et al., 2009)
  - engagement in high risk behaviours, including non-compliance with medical treatment (Mellins, et al., 2009)
  - poses a significant public health threat for HIV transmission to others

- Mellins, C.A., Brackis-Cott, E., Leu, C.S., Elkington, K.S., Dolezal, C., et al. (2009). Rates and types of psychiatric disorders in perinatally human immunodeficiency virus-infected youth and seroreverters. *Journal of Child Psychology & Psychiatry*, *50*, 1131-1138.
- Mellins, C. A., Elkington, K.S., Bauermeister, J.A,. Brackis-Cott, E., Dolezal, C., et al. (2009). Sexual and drug use behavior in perinatally-HIV-infected youth: Mental health and family influences. *Journal of the American Academy of Child and Adolescent Psychiatry*, *48*, 810-819.

CHAMP+: Supporting HIV-infected youth and families (NIMH-1 R34 MH072382 01A1-02, PI McKay)

NY CHAMP+ curriculum is focused on:

- 1) Impact of HIV on the family
- 2) Loss and stigma in relation to HIV
- 3) HIV, health, and antiretroviral medication protocols;
- 4) family communication about puberty, sexuality and HIV
- 5) parental supervision and monitoring related to sexual possibility situations and sexual risk taking behavior, as well as helping youth manage their health and medication
- 6) social support and decision making related to disclosure.

CHAMP+ NY Findings

- <u>Post-intervention results:</u>
- Increase in child reports of caregiver supervision & monitoring of peer-based activities (t= 2.53, $p < .05$)
- Significant improvements in child emotional symptoms (t=3.1, $p < .01$)
- Decrease in caregiver reports of difficulties with youth
- (t= 2.50, $p < .05$)
- Decrease in conduct problems (t=2.2, $p < .05$) and functional impairment (t=2.9, $p < .05$)
- Families began to work more cooperatively on ARV medication issues (t=2.0, $p < .1$) at 3-month follow-up

Team: Mary McKay (PI), Claude Mellins (Co-I), Elaine Abrams (Co-I), Elizabeth Brackis-Scott, Stacey Alicea, Ezer Kang, Gisselle Pardo, Natalie Humphrey

Socio-cultural adaptation of CHAMP+ SA Qualitative Findings

- In-depth qualitative interviews with HIV+ adolescents (25), caregivers (15) & service providers (12)
- Themes
  - Loss & bereavement
  - Difficulty negotiating heterosexual relationships
  - 'Spoiled' identity
  - Difficulty negotiating peer pressure to engage in high risk behaviours
  - Disclosure difficulties'
  - Adherence difficulties
  - Positive coping – social support (adolescents & caregivers)

Socio-cultural adaptation of CHAMP+

- Interactive follow up focus group held with participants of qualitative study
- Investigators, facilitators, parents, youth, cartoon artists, social workers all participated in examining findings
- Artists and investigators engaged in construction of story line around themes of relevance
- Parallel process of developing work books for facilitators

Specific Aims

- Examine the preliminary impact of CHAMP+SA on short term proximal outcomes:
  - **Youth process** (coping, HIV knowledge, self esteem)
  - **Family/social process** (communication, support, supervision)
  - **Youth behavioral health outcomes** (mental health, medication adherence & participation in situations of sexual & drug use possibility)

CHAMP+ SA Curriculum

Resulting Vuka Family Project is a continuation of the CHAMPSA AmaQhawe Family Story and includes 10 session topics:

- Session 1 – Introduction/Surviving loss and bereavement
- Session 2 – What is HIV?
- Session 3 – Adherence
- Session 4 – Identity, Acceptance and Coping
- Session 5 – Disclosure
- Session 6 – Communication
- Session 7 – Puberty
- Session 8 – Dealing with Sexual Relations, Risk Behaviour & Peer Pressure
- Session 9 – Dealing with Stigma
- Session 10 – Support Networks

The Vuka Family

MA'MAFUTHA BAB'VUKA GOGO MUZI NONHLANHLA & NHLANHLA SINDI

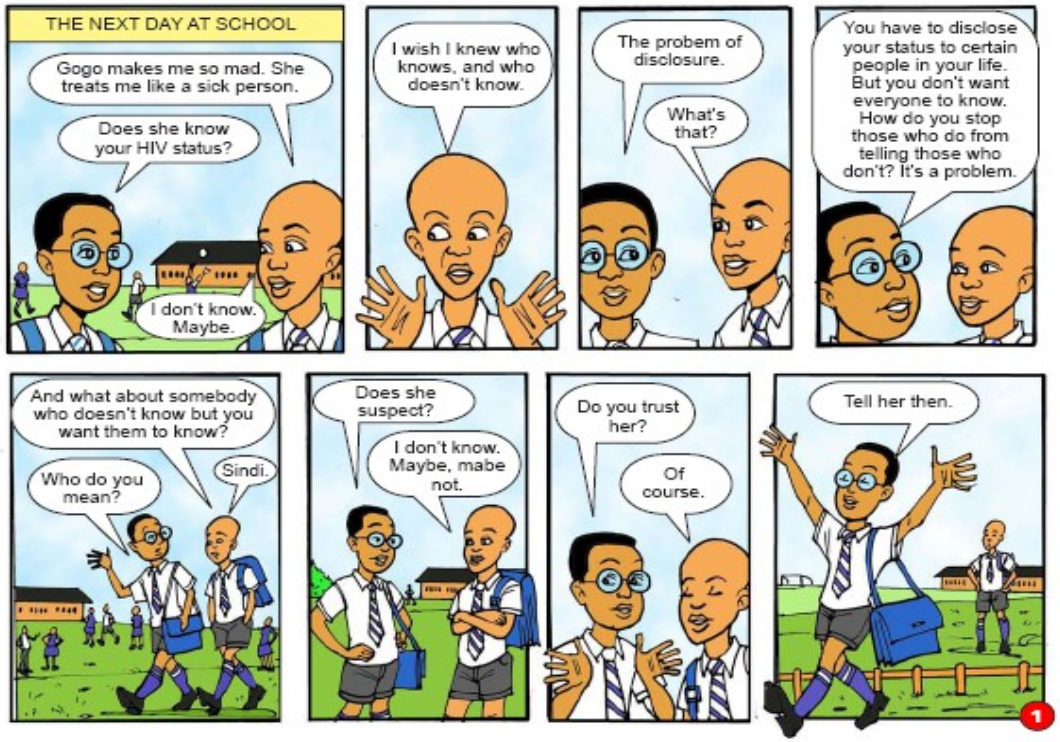
Surviving Loss and Bereavement

Adherence

MAMAFUTHA, THEMBA AND NONO GO IN TO SEE SISTER PATIENCE.
Today we are going to talk about you medication. Themba, do you have a good memory?
Yes, I think so...
2
That's good, because it's going to be very important for you to remember to take your medication every day.
Once you begin taking the medication, you have to take it every day. You must not miss a day. If you forget to take it, even just once, it gives the virus a chance to reproduce itself more quickly.

Youth Identity

Disclosure


THE NEXT DAY AT SCHOOL
Gogo makes me so mad. She treats me like a sick person.
Does she know your HIV status?
I don't know. Maybe.
I wish I knew who knows, and who doesn't know.
The probem of disclosure.
What's that?
You have to disclose your status to certain people in your life. But you don't want everyone to know. How do you stop those who do from telling those who don't? It's a problem.
And what about somebody who doesn't know but you want them to know?
Who do you mean?
Sindi.
Does she suspect?
I don't know. Maybe, mabe not.
Do you trust her?
Of course.
Tell her then.
1

Process outcomes

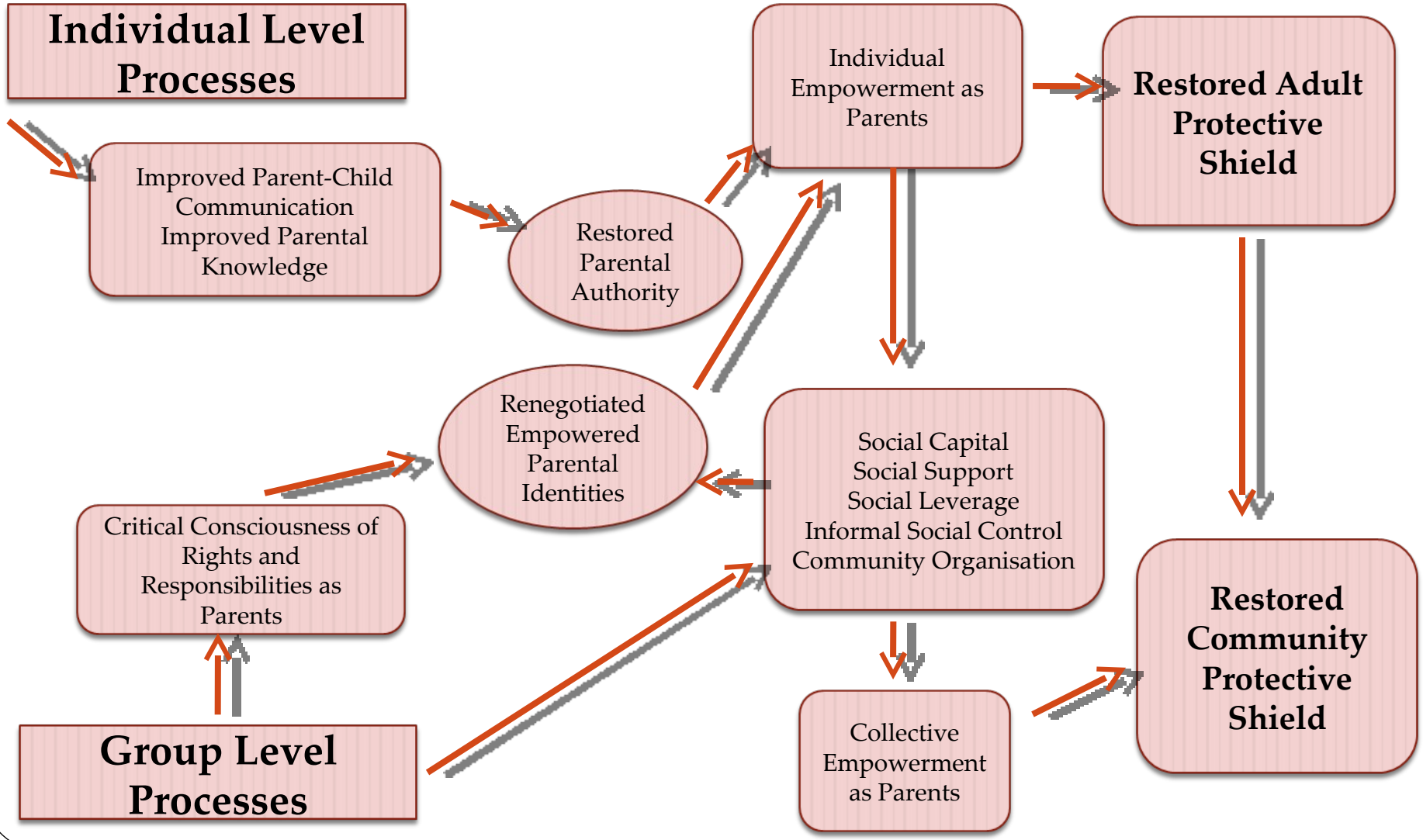
- Acceptance of HIV status
- Decreased internalised stigma
- Decreased externalised stigma
- Improved self concept and future orientation
- Improved mental health
- Improved adherence
- Improved HIV knowledge
- Improved communication

Concluding Comments

- Individual level change can co-occur with group level changes mediated through the family process
- Two year process evaluation follow up showed parents reported improved sense of self-esteem
- Together with social support from improved social networks empowered parents to act more effectively in relation to parenting
- Both individual and collective parenting helped strengthen the adult protective shield.
- Shift in focus to HIV+ youth and their families

Understanding Processes of Change within CHAMP

Paruk, Z., Petersen, I., Bhana, A. (2009). Facilitating health enabling social contexts for youth: A qualitative evaluation of the pilot study of a family-based HIV prevention programme. *African Journal of AIDS Research, 8*(1), 61-68



Acknowledgements

- **Youth HIV risk in a South African township NIMH (5 R01 MH64872-02)**
  - Principal Investigator: Carl Bell, MD.
- **CHAMP+: Supporting HIV-infected youth and families NIMH (1 R34 MH072382 01A1-02)**
  - Principal Investigators: Mary McKay, Ph.D., Claude Mellins, Ph.D., Elaine Abrams, MD
- **Adapting CHAMP+ for South Africa: Supporting HIV-infected youth and families NINR (R21 NR010474-01)**
  - Principle Investigator: Claude Mellins, PhD
    - Victor Daitz Foundation
    - Mason & Associates
    - Staff and Management of McCord Hospital
    - Friends of McCord