2 Positive Youth Development Approach to Support Life Skills of Young People with Chronic Conditions

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2.1 Introduction

As increasing numbers of adolescents and young adults (AYA) with childhood onset chronic conditions (COCC) are surviving into adulthood, the question of how to best support them has become increasingly important. These AYA with COCC deserve to not only grow up, but to thrive. This chapter focuses on Positive Youth Development (PYD) as a way of promoting positive outcomes for this population, such as social connectedness, enhanced confidence, community engagement, and increased prosocial behaviours. PYD is conceptualized as a developmental process, an approach to helping youth succeed, and the instances of youth programs that incorporate this theory. We begin by providing an overview of the societal context in which the PYD framework developed, including the shift to viewing youth as assets to be developed, rather than problems to be fixed. PYD posits that interactions between an individual and their environment are essential to promote developmental outcomes. We then explore a plethora of developmental theories that provide the basis for an empirically supported PYD approach, including Lerner and Lerner's 5Cs model of PYD, in which thriving is conceptualized as the growth of Competence, Confidence, Character, Connection, and Caring. Application of PYD principles to AYA with COCC is the focus of the remainder of the chapter.

The concept of AYA with COCC as a high-risk group is introduced, alongside research examining comparisons with peers without chronic conditions. While many AYA with COCC are eventually able to thrive, there may be marked differences in educational, vocational, and social outcomes [1–3]. For these reasons, applying a developmental, strengths-based approach to this population is crucial. We present research on PYD-based programming for AYA with COCC and bring

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attention to gaps in the literature. The "Big 3", including (1) opportunities for leadership, (2) emphasis on development of life skills and (3) sustained and supportive youth–adult relationships, are highlighted as essential components of youth programming to promote PYD in AYA [4]. Mentor relationships, opportunities for leadership, and summer camps for youth with COCC are opportune settings to integrate PYD components to enhance outcomes for AYA with COCC.

Recommendations on how to incorporate PYD components into both youth programming and interactions within the healthcare field are provided. While there is some research on PYD interventions for AYA with COCC, the need for rigorous evaluation continues; a variety of measures for examining PYD programming are suggested and reviewed. Increasing PYD has been linked to increases in competence and confidence, which can help empower young people to be more actively engaged in their own lives. AYA with COCC need to become independent in managing their healthcare, thus exposure to PYD components may aid in their development of life and healthcare transition skills. Since PYD focuses on the interaction between a person and their environment, and AYA with COCC often spend a significant amount of time in medical settings, understanding ways to encourage positive development and integrate it into healthcare may provide additional tools to promote successful adult development and improved health outcomes for this population.

2.2 The History and Evolution of Positive Youth Development

Positive Youth Development is a theory and an approach that is rooted in developmental psychology and conceptualizes youths as inherently capable of living positive and productive lives. In order to understand the PYD approach and model, it is important to appreciate how the field of youth development and youth development programs evolved. In the United States, in the late 1800s/early 1900s, children regularly worked at a young age, often in unsafe conditions. In the early 1900s, child labour and compulsory education laws began to gain support in the States [5], and youth development programs started providing educational and supportive services to children and adolescents. Many early programs were focused on providing safe places to help youth develop into productive, contributing members of society [6]. In 1938, Congress passed the Fair Labor Standards Act, which regulated child labour [7]. As more children were expected to attend school to a later age and were not allowed to work, the need for youth development programs increased. These early programs often included practical skills that youth could use in later life.

In the 1960s, there was a shift in societal thinking about youth, where the potential for self-destructive behaviour was emphasized, which led to a focus on "fixing" kids [8]. In response to the idea that youth were troubled and likely to engage in risky behaviours, programs began to focus on prevention of problems, such as drug use, drunk driving, gang affiliation and teenage pregnancy. This focus on risk behaviours and preventing delinquency fostered a negative lens through which to view

youth. Rather than seeing adolescents' potential and ability to grow and contribute to society, programs and practices were developed to avoid or mitigate problems and negative outcomes. This "problem-youth tradition" contributed to viewing and characterizing adolescents as a problem to be fixed rather than as a resource to invest in and nurture [9].

By the 1980s, the idea that youth are typically *not* troubled and can be successful contributors to society began to gain traction. With this view of youth as having inherent positive qualities that could be utilized and harnessed, positive youth development theory began to solidify, leading to the growth of programs to help youth develop in positive, normative ways. This shift in how adolescents are portrayed resulted in a substantial increase in the use of strengths-based approaches to adolescent development by researchers, practitioners and policymakers. These efforts were derived from theories and philosophies of the positive youth development perspective, which underscored the importance of fostering the adolescent's strengths and capacity to thrive, rather than solely focusing on mitigating or eliminating risk behaviours [10].

In order to promote positive outcomes, the PYD framework also examines alignment between youths' strengths and the resources in their surroundings or community [11]. PYD scholars propose that all young people have strengths, and that their surrounding contexts, including other individuals, such as parents or mentors, and institutions, such as schools or programs, can provide them with resources that promote their development. These ecological factors have been positively associated with indicators of PYD and inversely related to risk behaviours [12]. When the strengths of youth are aligned with resources in the environment, positive outcomes and youth thriving are promoted.

There are several theories in the PYD tradition that have led to the current model of PYD. William Damon [9] wrote about adolescence as a time period where individuals start to explore their sense of purpose. Early research in the field indicated that motivation is developed when youth are able to identify their passion. This sense of purpose helps youth to have prosocial behaviours, commitment, achievement, and self-esteem; it also allows youth to identify moral values. Defined as, "a stable and generalized intention to accomplish something that is at once meaningful to the self and of consequence to the world beyond the self" [9], purpose is a combination of action-oriented goals, both short and long term, of one's desire to make a difference in the world and find meaning in his or her life [13]. Purpose is often viewed differently in adolescents and adults, and there may also be differences based on gender, socioeconomic, and cultural differences [13].

Peter Benson and the Search Institute examined developmental assets that young people should successfully develop, which formed the basis of the 5Cs as will be discussed. They identified 40 assets that serve as the building blocks for healthy adolescent development. These assets are organized into two broad categories—internal and external. Internal assets include commitment to learning, positive values, social competencies, and positive identity. External assets consist of family/school/community supports, empowerment, boundaries and expectations, and constructive use of time [14]. There have been multiple studies that show the additive

nature of these developmental assets, with young people with more assets faring better than those with fewer. Both genders show similar patterns, with higher levels of assets correlating with lower levels of risk behaviour and higher levels of indicators for thriving. Therefore, these assets have the potential to compensate for socioeconomic status differences.

Between 2000 and 2002, the National Research Council and Institute of Medicine's Committee on Community-Level Programs for Youth met to determine the current state of youth programming in the United States and examined the social forces that led to changes in family/community life and expectations for young people [15]. They discovered several important factors negatively contributing to youth development, including weakening of community support, more parents working outside the home, greater exposure to violence in the media, and the extension of adolescence into the mid- to late-twenties. Since youth who have these unmet psychosocial needs are at higher risk for problem behaviours, they need enhanced supports. Thus, the committee determined, "young people need skills, knowledge, and a variety of other personal and social assets to function well during adolescence and adulthood" [15]. The universal themes identified were feeling competent, being connected socially, and having one's physical needs met. The committee recommended that community programs offer opportunities for youth to acquire developmental assets in positive settings as a means to reduce risk.

One such conduit of supporting youth development is through mentoring. Reed Larson added to the field of PYD by examining how mentoring relationships support development and youth agency. Based on Piaget's developmental theories, in which children are biologically wired to adapt to their environments [16], Larson [17] viewed young people as individuals who are "motivated and able to be constructive agents of their own development". Larson introduced the importance of this need to adapt and learn, which continues into adulthood. Individuals are more motivated to take on challenges when they have ownership over their actions, and, in turn, motivation supports learning and development. Larson found that mentoring interventions can work to change obstacles in daily life that may inhibit building developmental assets and that the input and guidance of the adult helps to support the youths' experience of agency, allowing the youth to navigate future situations independently. Larson's work contributes to the current model of PYD by exploring the positive effects of sustained youth–adult relationships.

The PYD framework has been further developed and studied by Lerner and Lerner and their 5Cs model of PYD [18]. The current formulation of the 5Cs model of PYD has evolved with contributions from the theorists mentioned above and the work of several other developmental scientists [19–21]. From 2000 to 2003, the current formulation of the 5Cs model emerged including Competence, Confidence, Connection, Character, and Caring (Table 2.1). The development of these components is aligned with Benson's earlier work on developmental assets, as all 40 assets can be mapped to at least one of the 5Cs. Competence is related to not only having the ability to perform a task well, but also to having a sense of related self-efficacy or perceiving that one can perform the job successfully. In terms of confidence, an individual must have an overall sense of self-worth. While individuals may be

Table 2.1 Definition of the 5Cs of positive youth development

Domain	Definition
Competence	Abilities/skills as well as a positive view of one's abilities/skills in domain specific areas, including social, academic, cognitive, and vocational
Confidence	An internal sense of overall positive self-worth and self-efficacy
Connection	Positive bonds with people and institutions that are reflected in bidirectional exchanges between the individual and peers, family, school, and community, in which both parties contribute to the relationship
Character	Respect for societal and cultural rules, possession of standards for correct behaviours, morality and integrity
Caring	A sense of sympathy and empathy for others

confident in certain abilities or actions, to fully meet this "C" a person has to have a positive self-image. Connection is related to the bonds that individuals form with the people and institutions in their lives. It is insufficient to just form ties—young people need to be active agents in these relationships. Character encompasses many assets and is related to how an individual chooses to act within the world. A well-developed character would include understanding and choosing to follow societal standards for behaviour, morals, and integrity. The fifth C is Caring, which encompasses having a sense of both sympathy and empathy for others [18].

Over time, Lerner and Lerner provided robust empirical support for this model in the 4-H Study of Positive Youth Development [4]. 4-H programs are community- and school-based youth development programs designed to build leadership and life skills through applied or "hands-on" learning opportunities for youth between 8 and 18 years of age. The name, 4-H, refers to the organization's original symbol of a four-leaf clover with an "H" on each leaf, signifying head, heart, hands, and health. Initially designed to support youth in rural and agricultural areas, 4-H now serves youth in urban, suburban, and rural communities. 4-H programs aim to create safe environments for youth to build leadership skills and personal empowerment in the following areas: Science, Technology Engineering and Math (STEM); healthy living, including physical, mental and emotional health; and active engagement in the community [22]. In 2002 and 2003, over 7000 youth in the fifth grade participated in the 4-H study from 42 states, and, to date, it has followed youth through 11th grade. This study provides empirical support for the 5Cs model, and refined the PYD measure, which assessed the five components of PYD and its relationship to youth outcomes over time, such as higher contribution to society and reductions in risk behaviour [23, 24].

The 5Cs model postulates that greater PYD assets predict positive outcomes and reduced risk behaviours [15, 18, 25]. Figure 2.1 presents the Lerner and Lerner model of PYD which focuses on the bidirectional relationship between youth and the social ecology [24, 26]. As the figure illustrates, there are internal strengths of adolescents, such as hope, connection to school, and intentional self-regulation that can promote the development of PYD assets and are related to the ability of youth to take advantage of ecological resources. Ecological assets can promote the development of PYD through supporting the development of adolescents' strengths. One

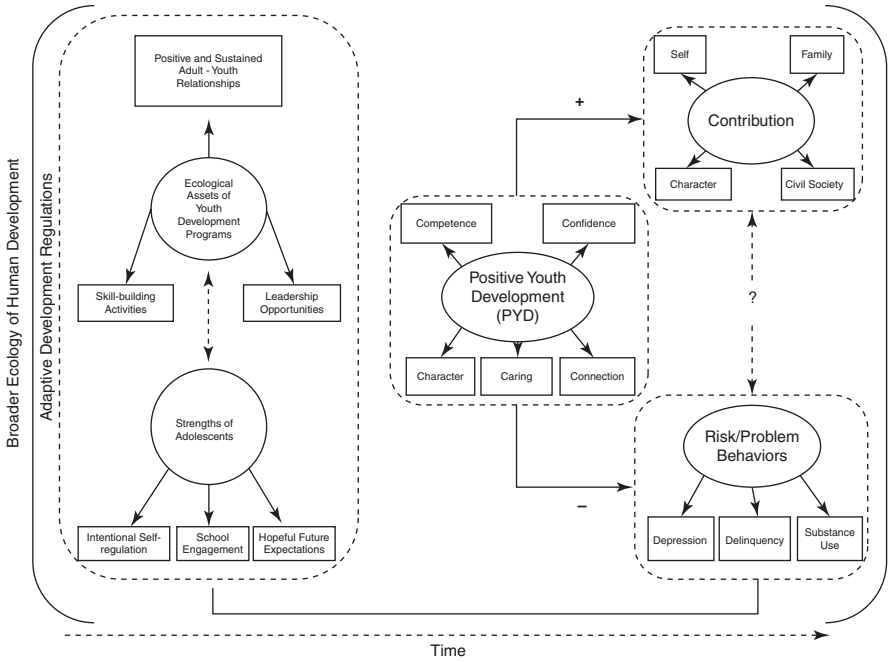

Fig. 2.1 Lerner and Lerner developmental systems model of positive youth development. (Used with permission from Richard M. Lerner; complete reference to the previous publication)

primary positive outcome is the sixth C—Contribution, defined as youth's ability to contribute to society. Youth that demonstrate high scores across the 5Cs are more likely to demonstrate greater educational and career achievement, and lower risk and problematic behaviours [24]. As a result of increases in positive internal and external attributes, the theory also postulates that youth are able to actively contribute to their own development while also enhancing their environment [27].

Empirical findings spanning a range of individual and ecological assets, including studies of mentoring, parent closeness, school connectedness and participation in spiritual or religious activities and programs have supported the PYD framework [28–31]. For example, parent-family connectedness and school connectedness are protective against risk behaviours in many domains, including substance abuse, emotional distress and violence [27]; family closeness has been associated with greater self-esteem and social competence, and fewer problem behaviours [32]; and the presence of a mentoring relationship has been shown to promote high school graduation, college attendance and employment for youth [33–35]. Other studies have focused on the quality of PYD programming provided and its impact on youth outcomes. A 2018 review of program evaluations found that programs that promoted more skill-building were associated with greater change in social conscience and character, and promoting positive social norms within the program was associated with a greater impact on youth's values, decision-making and critical thinking skills [36].

2.3 Applied Positive Youth Development and Outcomes

Similar to the paradigm shift in the understanding of health as more than the absence of illness, the National Research Council and Institute of Medicine's Committee on Community-Level Programs for Youth identified that "problem-free is not fully prepared" [15]. Meaning that youth who have multiple positive developmental assets and are not considered at-risk may not be fully prepared to take on the responsibilities of adulthood. It also means that removing a problem, such as a high-risk behaviour, may not be enough to create lasting success. Even with multiple positive factors in a young person's life, they must have opportunities to be exposed to and master a variety of life skills. This recognition encouraged programs to not only work towards the prevention of problems, but also encourage development and acquisition of life skills.

Historically, many community-based youth programs in the United States were designed to be appealing to youth of European descent [6]. Over time, the need for programs to support youth from low socioeconomic and ethnically diverse backgrounds was identified [37]. Many organizations developed new program opportunities for minority youth. Unfortunately, low-income African American, Latino, and Native American youth have not participated in youth programs to the same degree as their middle-class, European American peers [6]. While many youth programs began with a goal of reaching marginalized youth, the popularity and growth of programs for middle-class youth may have left out many marginalized youths for whom the programs were originally targeted.

As the PYD theory developed, there has been greater effort placed on determining what characterizes a PYD program. Broadly, a PYD program is one that contributes to adolescents becoming happy, healthy, and productive adults. As described in the previous section, there are multiple youth development theories with significant overlap. There is also considerable debate about *how* programs contribute to healthy adolescent development.

Empirical research supports the role of community-based youth programs in promoting positive outcomes and reducing risk behaviours for youth. The National Research Council and the Institute of Medicine also examined data regarding community programs designed to promote youth development. The findings from this report included a broad description of features of positive developmental settings including safety, appropriate structure, supportive relationships, opportunities to belong, positive social norms, support for efficacy and mattering, opportunities for skill-building, and integration of family, school, and community efforts [15]. This report built on earlier work of the Positive Youth Development Project in 1999, which examined the effectiveness of youth programs [38]. They identified a wide range of shared components including strengthening competency, building self-efficacy, and increasing healthy bonding between adults and peers. Effective programs provided structure and demonstrated consistent program delivery over the course of 9 months or more.

Roth and Brooks-Gunn built on this earlier work, examining community-based programs with the intent of describing the essential components of youth

development programs [21, 26] including (1) active participant involvement; (2) a safe, caring environment that treated adolescents as responsible individuals; and (3) goals focused on developing prosocial behaviours and life skills [21]. Even when programs involve preventing problem behaviours, PYD programs have a primary goal to promote positive development. PYD programs utilize an "atmosphere of hope" ([18], p. 97) that is youth-centred and gives participants the opportunity to take on responsibility, make choices, and grow. The activities in PYD programs can provide both formal and informal opportunities for skill-building, engagement in real-life challenges, and exposure to new ideas and experiences [21]. While programs have similarities within these three characteristics, how individual organizations implement them vary.

Roth and Brooks-Gunn [21] surveyed 71 youth organizations which used PYD to further define essential programmatic components. In the program goals section, the majority of the programs had missions related to youth developing skills, connections, and competencies, while also preventing health-compromising behaviours. In the program atmosphere section, important themes included relationship-building activities to promote a supportive environment, leadership and youth decision-making to empower participants, and expectations for positive behaviour. Interestingly, programs that had a prevention goal tended to meet for fewer hours overall, were less likely to offer mentoring, and were less likely to create an empowering environment. Programs that focused on social connection demonstrated greater staff/volunteer retention. More than 75% of organizations provided programming with recreational activities, opportunities to broaden their horizon, real-life based "authentic" activities, and/or life skill, social skill or leadership training. The specific focus of the activity was less important than the opportunity to participate. Once again, programs with prevention goals tended to have lower levels of skill-building components, chances to broaden horizons, or authentic opportunities. This study also indicated that larger programs may have more difficulty in creating supportive program environments, although the budget per participant did not lead to specific program differences. Both large and small programs were able to create supportive environments that led to positive developmental opportunities.

PYD program characteristics identified by Catalano et al. [39] and Roth and Brooks-Gunn [21] overlap with Lerner's "Big Three" characteristics, which include: (1) opportunities for youth participation in and leadership of activities; (2) emphasis on the development of life skills; and (3) sustained and caring youth–adult relationships [10]. A review examining the effectiveness of programs oriented to promoting PYD among youth found that programs that demonstrated improvements in youth outcomes, such as quality of peer and adult relationships, problem solving, self-control, and academic achievement [38]. Individual features of the programs focused on strengthening social, emotional and behavioural competencies; enhancing self-efficacy; providing clear behavioural standards; increasing bonds between youth and caring adults and peers; providing opportunities for recognition and

delivering programming with consistency and structure over a sustained period of time of 9 months or longer. These program features allowed AYA to gain developmental assets that led to the overall outcomes [39]. Roth and Brooks-Gunn characterize PYD programs as those that create safe, supportive, and empowering spaces that focus on skill-building, developing self-confidence and confidence for the future, and building connections with others. Similarly, Lerner's "Big Three" model provides essential components to distinguish *how* PYD programming can promote and enhance the 5Cs. While different programs may implement the "Big Three" in a variety of ways, they are important to the development of the 5Cs. Developing the 5Cs helps lead to the sixth C, Contribution, and studies have shown that the more developmental assets an individual has attained, the greater the effect on positive outcomes [40, 41].

The relationship between these characteristics and enhanced PYD continues to be an active area of research. Ramey and Rose-Krasnor [42] argued that it is important to not only examine whether or not youth participate in quality programs, but specifically how youth interact within the context of the program. They argued that it is necessary to examine in detail the interactions between youth and a program to understand the relationship between program activities and the subsequent development of PYD assets.

Policy makers and public health officials are interested in using youth development programs to reduce problem behaviours. A 2003 report by the Forum for Youth Investment focused on the importance of thinking broadly about youth development for all youth to reduce problem behaviours, promote positive outcomes, and broadly prepare youth for adulthood [43]. The importance of youth participation in programming outside of school has been incorporated into the Healthy People 2020 objectives, with the goal of increasing the proportion of youth who participate in outside of school activities by 10% [44]. Youth programs are an important tool to promote the development of youth at the local and national level.

With the growth of PYD programs, the need for evaluation has also been highlighted. A confounding factor in determining the efficacy of these programs is that, as described above, there is no set definition of a PYD program. While there are principles that have been deemed important, there are variations in the terms used to describe these principles. Additionally, simply stating that a program is PYD focused does not necessarily mean that it contains the Big Three or emphasizes growth through the 5Cs.

Given promising findings in at-risk youth, the PYD approach can be applied to other populations, such as AYA with COCC. Focusing on developing internal youth assets by building skills and competency through the experience of safe connections with caring adults, PYD programs and approaches can be applied to a variety of communities and organizations that aim to support adolescents as they transition into adulthood. In particular, this approach is especially relevant for programs or entities that serve youth with chronic conditions who would benefit from opportunities to build life skills, leadership and connections within their community.

2.4 Positive Youth Development and Chronic Conditions

More than 15% of adolescents live with childhood onset chronic conditions (COCC) including diabetes, sickle cell disease, inflammatory bowel disease, physical disabilities and other conditions [45, 46]. Along with environmental, health behavioural, and genetic changes, advances in medical technology over the past four decades have led to substantially increased life expectancy for many youth with COCC, with significantly more youth with chronic conditions now surviving into adulthood [47, 48]. With this transition to adulthood, youth with COCC face multiple challenges, including suboptimal educational, vocational and financial attainment, poor health outcomes due to inadequate self-care, halted health care transition, risk-taking behaviours, as well lower levels of psychosocial adjustment and quality of life [3, 49, 50]. Therefore, it is imperative to conceptualize ways to support this population in becoming successful young adults in all areas of life. There are many aspects of PYD that make it an ideal framework to use in programming for youth with COCC, such as focusing on youths' strengths, aligning youths' strengths with their contexts, honing skills, and promoting attributes such as competence, self-determination and self-efficacy, which have been shown to promote the successful transition to adulthood [18, 51].

A comparison of positive youth development for adolescents with and without COCC provides initial evidence that approaches used to promote positive outcomes among youth without COCC can be applied to youth with COCC. Surprisingly, there were no significant differences between adolescents with and without COCC on overall PYD or any of the 5C domains. Confirmatory factor analysis demonstrated that the same structure of PYD as measured by Lerner in the general population can be applied to youth with COCC [52]. These findings suggest that PYD-based interventions for youth without COCC are applicable to youth with COCC. An unpublished manuscript evaluating rates of participation in general youth programming among youth with and without COCC found that adolescents with COCC were just as likely as their peers without COCC to be engaged in youth programming, indicating that these programs may be sites to target PYD-based practices [53]. Another finding from the analysis indicated that Latino and other ethnic and racial minority youth were significantly less likely to participate in youth programming. Therefore, programs that serve youth with chronic conditions should take additional steps to include youth of diverse ethnic and racial backgrounds.

Historically, studies of youth with COCC have taken a problem-focused approach rather than concentrating on youths' strengths. Living with a chronic condition is often considered a challenge that one must overcome. Youth with COCC are a vulnerable population at risk of becoming over-medicalized and are especially in need of a strengths-based framework for positive growth.

Like populations for which PYD was originally conceptualized, youth with COCC are an underserved, at-risk group. Indeed, rates of delinquent behaviour are comparatively high in this population given the increased health vulnerability of these youth, and these maladaptive behaviours may have more detrimental effects [54, 55]. For example, a teenager with diabetes who uses alcohol may not recognize a low blood

sugar and become comatose; a young adult with asthma who is non-adherent with their treatment regimen is at risk of death from a fatal asthma attack. For youth with COCC, the stakes are higher in the case of risky behaviours, and therefore the need for targeted intervention is even more imperative. The PYD approach has been used to promote positive health behaviours and decrease risk behaviours for at-risk youth in the areas of sexual health and substance use [56, 57]. Analysis of these programs indicates that wellbeing in adolescence is associated with decreased health risk and improved general health in young adulthood for youth without COCC [58]. Based on this data, youth with COCC could substantially benefit from PYD-based programs in terms of health outcomes in the context of risky behaviours.

The PYD framework of aligning youths' strengths with resources in their environment to promote optimal development has been applied to high-risk populations of youth with success in promoting positive outcomes. For youth with COCC, leveraging ecological assets is even more essential. Youth with COCC are often isolated from their community [59] related to a number of factors including school absences [53], lack of programs that can accommodate youth with disabilities, higher rates of mental illness, or other challenges [60]. The PYD approach enhances the alignment between an individual's strengths and environmental resources, thus fostering community, which is critical for youth with COCC. It has been shown that enhancing community connectedness, especially in schools, promotes educational attainment for youth with COCC [34], a critical factor in future financial stability and success in adulthood. Similarly, evaluations of PYD programs have demonstrated improved mental and physical health, enhanced resilience, and overall quality of life for youth without COCC [38, 61]. While some studies have shown higher quality of life among adults with serious health conditions, known as the disability paradox [62], research has also found higher rates of mental health conditions among youth with COCC compared to youth without COCC [60, 63]; therefore, the benefits of PYD programming have the potential to be extended to the chronic illness population with valuable implications.

For positive development to occur, youth must become activated, motivated and engaged in their own development [17]. According to Larson, PYD assumes that a young person has the inherent capacity to derive motivation through challenge, which serves to galvanize that individual's active engagement in their development. Many youths with COCC face challenges on a daily basis related to their condition, which may provide the motivation to catalyze engagement. For youth with COCC, this is especially important given the additional burden of caring for their chronic condition and its implications on health outcomes. If youth are motivated to engage in their development, that motivation may extend to increased engagement in their health management and health promotion leading to improved overall wellbeing.

AYA with COCC struggle with the transition to adulthood in vocational, educational and financial areas. They are less likely to graduate from college, obtain gainful employment, and earn less income compared to their healthy peers [64, 2, 3]. In addition, the period of healthcare transition from paediatric to adult medicine presents a high-risk period for youth with COCC and is associated with increases in morbidity and mortality [65–67].

Transition readiness, or the ability of adolescents and their family to engage in the process of moving from paediatric to adult care, has been conceptualized as a developmental skill important to consider in the context of other developmental tasks that adolescents with chronic conditions are acquiring as they mature [68]. Transition readiness has been linked to other youth development constructs that are associated with PYD including intentional self-regulation (ISR) and hopeful future expectations (HFE). ISR involves the process of selecting and setting goals, using skills to optimize one's chances of successfully achieving those goals, and compensating or altering one's trajectory if attempts at actualizing goals fail [69]. ISR is a modifiable developmental skill that could be promoted with PYD-oriented programming and is particularly relevant to youth with COCC who may have to adjust life goals in the face of condition-related challenges. ISR has been shown to be associated with transition readiness in youth with COCC [68]. Self-regulation has been conceptualized as instrumental to chronic condition self-management via its effect on individual and interpersonal processes [70]. HFE may facilitate the development of transition readiness as well given its influential effect on ISR [71]. Since more advanced developmental skills are tied to enhanced transition readiness, encouraging positive youth development for youth with COCC may also enhance transition outcomes, both related to healthcare transition and transition into adulthood.

According to the PYD framework, successful youth outcomes include the development of attributes of competence, confidence, character, social connectedness and compassion, known as the 5Cs described above [39]. Competence and confidence are two internal PYD assets that are important for promoting and ensuring optimal self-management through activation—a critical skill for youth with COCC. Patient activation is defined as the individual's knowledge, skill and confidence in management of their own health [72], and there is increasing evidence supporting the importance of activation in promoting positive outcomes for people with chronic conditions [73, 74]. Healthcare transition is defined as a "multifaceted, active process that attends to the medical, psychosocial, and educational or vocational needs of adolescents as they move from the child-focused to the adult-focused health-care system"; it involves the development of autonomy and independence, as well as transition in other areas of the youth's life, such as school, work, and the community [75]. Higher activation scores on the Patient Activation Measure have predicted transition readiness in a study of AYA with rheumatic disease [76] suggesting that targeting activation could improve healthcare transition. Health literacy and numeracy scores in this same cohort did not predict transition readiness, consistent with the finding that knowledge alone is not sufficient to promote improved patient engagement and outcomes [77]. For youth with COCC, it is not only paramount that they understand their condition, symptoms, and management, but that they have the confidence to carry out their treatment plans and advocate for themselves in order to become successful and healthy adults. Both competence and confidence have been associated with enhanced patient activation [72] and are promoted through PYD programming.

Hibbard et al. [72] conceptualized a 4-stage developmental model of activation: (1) believing in the importance of the individual's role in their healthcare, (2) having the *confidence* and *knowledge* (or competence) necessary to take action, (3) taking action to maintain and improve one's health, and (4) staying the course under stress. Of note, "staying the course under stress" can be understood as ISR in the PYD framework. Higher levels of patient activation have been associated with decreased unnecessary healthcare utilization and improved health outcomes [73]. It is clear that essential components of PYD influence activation. Thus, improving positive development in youth with COCC on a broad level may improve transition readiness and health outcomes via patient activation [68].

PYD programming for youth with COCC fosters the development of successful young adults who are active contributors to their communities, and is an opportune forum for helping youth become active and engaged self-managers of their condition and their lives. The effectiveness of the PYD approach in fostering positive outcomes for youth with COCC was examined by Maslow and Chung [78] in a systematic review of programs for youth with COCC that employed principles of PYD. Fourteen youth programs (15 studies) were identified that included at least one core component of PYD. Only three studies were considered comprehensive (included all three core elements of PYD programs: opportunities for leadership, skill-building and sustained relationships with adult mentors). Four programs were mentoring-based (promoted sustained youth–adult relationships), and seven focused on youth leadership (youth were actively involved in program leadership). Below, we present different types of programs that could be leveraged to support PYD in youth with COCC based on this review of the literature [78]. The review identified programs employing some combination of PYD principles and underscores the variety of programs that could be harnessed to promote PYD.

2.4.1 Mentorship

By harnessing the connections among AYA, peer-based mentorship provides a mechanism to promote PYD. We recommend intervention models that integrate young adults who have successfully navigated the transition to adult care to serve in leadership roles to support their peers in navigating this arduous transition process to adult healthcare and adulthood. This model could be supported by one-to-one mentoring models in which mentors are individually matched with AYA, or in group settings with multiple mentors and youth meeting together. Peer-based mentoring interventions have shown to promote positive outcomes for AYA with chronic conditions, such as improved self-efficacy, empowerment and wellbeing [79], as well as improved self-care advocacy and reduced loneliness [80].

Group-based mentorship has been shown to promote PYD. For example, The Adolescent Leadership Council (TALC) and Adolescents Transitioning to Leadership and Success (ATLAS) programs, which are healthcare transition focused leadership programs based in hospital settings, bring together college mentors and high school

participants for monthly meetings. The programs encompass the "Big Three" PYD components and provide the opportunity for college mentors and participants to discuss ways to adaptively grow up with a chronic condition. Topic areas are chosen by youth participants; examples include 'talking to friends about one's chronic condition', 'speaking with the doctor independently', and 'identifying and obtaining accommodations in school'. College-aged mentors help develop programming activities, such as role plays, ice breakers, and instructional games. These programs also include a skill-building component, which allows participants to gain confidence and competence in skills that are related to successfully transitioning into adulthood and the adult healthcare system. With the oversight of medical staff, college age-mentors are able to provide support to high school participants. Mentors share their own experiences to help guide and support high school participants. These programs have been associated with positive outcomes and promote PYD [80, 81].

The Chronic Illness Peers Support Program (ChIPS), a well-established program located in Australia, also includes the three core components of a PYD program [82]. Following participation in weekly group sessions, youth can choose to participate in various social, educational, and leadership-based activities throughout the year. This program provides opportunities for youth to take on multiple leadership roles, such as serving as a group mentor/co-facilitator, fundraising, and engaging in advocacy. With activities occurring year-round, youth can develop sustained relationships with adults throughout the year, and develop a variety of important skills.

2.4.2 Leadership

Traditional leadership-based programs provide another mechanism to promote PYD elements. The leadership programs included in the systematic review described above include Outward Bound, camp- and school-based programs, which provide youth with COCC an opportunity to serve as leaders, support one another, and participate in program development.

Outward bound programs provide youth the opportunity to learn and develop while engaging in outdoor activities. Programs for youth with chronic illness have been effective in promoting short-term and long-term outcomes, including improvements in leadership, self-concept, and school attendance. The British Outward Bound program, for instance, was developed for youth with type 1 diabetes, in which youth participate in outdoor excursions while also having to manage their diabetes care [83]. This provides the opportunity for youth to learn essential self-management and problem-solving skills in a variety of conditions [78, 83]. It also provides an opportunity for youth to serve as leaders and support one another during challenging outdoor activities.

Another context in which to promote PYD is the summer camp setting. Summer camps dedicated to youth with COCC serve a large portion of youth with COCC [84]. Youth who attend camp are already engaged and have established relationships with camp counsellors and staff. Camps designed for youth with COCC could leverage these relationships to develop a PYD-based program

by complementing youth–adult sustained relationships with skill-building and leadership opportunities [84]. A recent systematic review evaluated all research studies conducted of camps for youth with COCC over the past century in the United States and examined whether the camps utilize PYD-based principles. Of the 425 studies reviewed, over 50% contained all three principles of PYD, and over 90% included at least two of the three components. Although studies did not directly address the three principles, this helps to underscore the opportunity for camps to integrate PYD programming [84]. Beyond the campers, research suggests that AYA counsellors with chronic conditions may also benefit from camp in terms of their condition self-management. At a camp for youth with diabetes, AYA counsellors with diabetes were found to have significant reductions in Haemoglobin A1C, a marker of blood sugar control, over 6–10 weeks at camp [85].

Maslow and Chung [78] highlight the need for more rigorous research to evaluate the impact of programs on the promotion of medical, healthcare transition, and psychosocial outcomes for youth with COCC. While all studies in the review assessed psychosocial outcomes, only four respective studies examined medical outcomes (e.g. glycaemic control, weight loss) and healthcare transition outcomes (e.g. self-advocacy, self-management). Psychosocial adjustment and empowerment improved in a mentoring program for youth with disabilities. Other studies demonstrated no change in self-worth, coping, self-esteem, locus of control and diabetes adjustment. These findings underline the lack of rigorous PYD-based program evaluations in AYAs with COCC, which limits the ability to comprehensively evaluate the efficacy of PYD-based programs.

2.5 Key Recommendations for Practice

Based on the current literature and our team's 20+ years of PYD programming for AYA with COCC, our recommendations are both broad and specific. Just as PYD has been conceptualized in many ways, with a variety of components, implementing PYD in practice can be achieved in myriad forms. In order to determine how to best utilize PYD, it is important to understand both the setting and overall goals. While most of the PYD research has been on structured programs, the same principles may be applicable in other settings.

When developing interventions for AYA with COCC, we recommend integrating the Big Three components of PYD principles. Firstly, this includes providing opportunities for AYA participants to establish positive and stable long-term relationships with adult role models. Secondly, integrating skill-building components into programing is essential; these could include skills specific to living with a chronic illness, such as self-management (i.e. treatment regimen adherence) and healthcare navigation (i.e. self-advocacy in the physician's office), as well as skills related to AYA more generally, such as educational and vocational related abilities. Third, programming should be intentional about providing leadership opportunities for AYA. There are various ways to provide leadership opportunities such as involving

AYA in program planning, incorporating AYA in mentorship roles, and enabling youth to develop and lead programs.

There is not one specific way to incorporate all three PYD principles into a program. We encourage program developers to be creative and innovative in forming developmentally appropriate, PYD-based programs. For many programs serving AYA with chronic conditions, modifications to current programming may lead to incorporation of more PYD components. Programs can complete self-assessments on how well they incorporate the Big Three into their current offerings, and then integrate additional principle(s) into the intervention model. For example, an Outward Bound program for AYA with chronic conditions may already be integrating sustained adult-youth relationships and skill building, and may consider incorporating leadership opportunities, such as enabling AYA to plan excursion or serve as mentors. PYD-based programs for youth with COCC have been implemented by individuals with various levels of expertise in a range of settings including the hospital, school, community, and online.

The Big Three are associated with promoting internal attributes consistent with Lerner's 5Cs: competence, character, confidence, connection, and compassion. Developmental theory and research have shown that as AYA develop more assets, their outcomes improve. Promoting the 5Cs may identify youth strengths and enhance assets, which can help AYA with COCC to thrive. ISR and HFE are two components described above that have been linked to PYD and enhanced transition readiness, and may be related to improved health outcomes. If it is not possible to integrate the Big Three into interventions, identifying which components of the 5Cs, ISR, and HFE best fit within the goals of an organization or program will allow for more targeted interventions. Additionally, being aware of the diversity of the target group will be necessary in order to create culturally appropriate and successful programs.

While current studies examining PYD programs for youth with COCC have many shortcomings, such as lack of control groups, small sample sizes, and limited follow-up, this creates an opportunity for growth. Moving forward, it is critical for researchers to use rigorous methods across studies and sites to better capture the development of positive youth attributes in AYA with chronic conditions over time. Rigorous methodologies aside from the standard randomized control trials may be more realistic, especially as many organizations that provide programming do not participate in research. Identifying new models to study these varied programs may help to mitigate these concerns while also serving as many AYA with COCC as possible. While there are currently a few measures to evaluate PYD that can be utilized for both informal assessment and research, further validation and study is needed.

We also recommend integrating aspects of PYD into healthcare practice. While healthcare providers are not necessarily mentors, they are adults in a young person's life who often have a positive influence longitudinally. Encouraging AYA with COCC to have a larger role in their healthcare may improve their motivation and compliance. Incorporating skill-building opportunities into office visits, such as answering health questions, giving a medical history, and/or making an appointment independently in the absence of parents, may help empower AYA with COCC and enhance both confidence and competence. When possible, including AYA with COCC in

decision-making, both for their own care and for broader clinic or systems issues may help promote leadership. These changes to practice may help AYA with COCC to develop more assets, which in turn may improve health outcomes.

2.6 Conclusion

Due to great medical advancement, the majority of youth diagnosed with a chronic condition will now survive into adulthood. These medical achievements have led to a greater focus on the long-term outcomes in this population. Developmentally based theories have been critical in moving from mitigating current physical and psychological symptomatology to promoting optimal development. PYD is one theory that can help to inform how to best support adaptive long-term development for youth with COCC. This chapter provides a historical overview of PYD, as well as its theoretical underpinnings. Lerner and Lerner's 5Cs model is introduced as an empirically supported approach, which posits that individual youth assets can predict long-term outcomes in at-risk youth. Initial evidence is described that demonstrates a good fit for applying Lerner and Lerner's 5Cs framework to youth with chronic conditions.

In sum, PYD can be leveraged to achieve optimal development of AYA with COCC and presents an area ripe for investigation in this population. This chapter presents the current state of knowledge on PYD programs in AYA with COCC. The recommendations for practice are outlined to provide guidance for professionals working with this population in various settings to promote PYD. While clinical implications for the importance of PYD in this population are highlighted, research in this area remains limited. This chapter should serve as a foundation for future research to better understand and promote PYD in AYA with COCC.

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