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Risk and resilience in developmental diversity: Protocol of developing ICF core sets

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Abstract

Despite facing more adversity and being at a greater risk of poor long-term outcomes, many neurodivergent individuals thrive and have a "good life" according to subjective and objective standards. Research and clinical practice have most often focused on risk and negative outcomes in neurodivergent individuals. In comparison, very little attention has been paid to resilience and positive outcomes, and individualized assessment of risk and resilience is required for this population. The International Classification of Functioning, Disability, and Health (ICF) provides a framework to examine positive functional outcomes and the factors important for risk and resilience in developmental diversity. This protocol describes the multi-phase process that will be undertaken to develop ICF Core Sets or sets of ICF codes most relevant to risk and resilience in developmental diversity. Core Sets for risk and resilience in developmental diversity will advance the understanding of outcomes in neurodivergent populations and will provide a basis for developing individualized tools to assess resilience and risk in this population.

Keywords

Neurodiversity, thriving, flourishing, positive adaptation, functioning

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Background and aim

Diversity is inherent to human nature and the human experience, and there are countless pathways in which an individual may develop. This developmental diversity results in unique personalities, ability profiles, and personal strengths and challenges (Armstrong, 2015; Chapman, 2019). Neurodivergent individuals, that is individuals whose development diverges from the dominant developmental profile, inclusive of prematurity and neurodevelopmental conditions, are part of this developmental diversity (please refer to Table 1 for a comprehensive overview of terminology and definitions within this protocol). Neurodivergence results in different ways of interacting with the environment (Hee Chung et al., 2020; Ismail & Shapiro, 2019), and there are numerous individual (e.g. genetics, mental and body functions, co-occuring conditions), social, and environmental (e.g. supports, physical and attitudinal environment) facilitators and barriers associated with functional, mental health, and well-being outcomes (Bölte et al., 2021).

Neurodivergent individuals can face a range of poor life outcomes, often reporting poorer quality of life compared to neurotypical peers (Cleaton & Kirby, 2018; Jonsson et al., 2017; Lee et al., 2016; van Heijst & Geurts, 2014;

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Table 1. Overview of terminology.

Term	Definition
Neurodiversity	The natural variation in individual profiles and developmental pathways resulting in unique personal strengths and challenges, encompassing all forms of development (both neurotypical and neurodivergent). It denotes that there is not only one standard (good) way to develop but that there exist many diverse pathways which are all valuable. The neurodiversity paradigm is not opposed to the concept of disability but instead proposes that disability arises not solely from an individual but due to a poor person-environment fit (Bertilsdotter Rosqvist et al., 2020; Chapman, 2019; den Houting, 2019).
Developmental diversity	Diversity in development and functioning across humans is a natural and valuable part of human variation. It embraces the neurodiversity idea that developmental differences are always to be understood in relation to context and specific moments in time beyond categorical boundaries (Hens & Van Goidsenhoven, 2023).
Neurotypical	The dominant neurotype or dominant way of developing and thinking (i.e. what might be considered 'standard', 'average' or 'typical'). It is a subcluster within neurodiversity.
Neurodivergent	Individuals who show developmental profiles that diverge from the dominant neurotype. Within the context of this project, neurodivergent encompasses individuals with a formal diagnosis of a neurodevelopmental condition according to the Diagnostic and Statistical Manual for Mental Disorders-5th Edition (DSM-5) (American Psychiatric Association, 2013) or International Classification of Diseases -11th Edition (ICD-11) (World Health Organization, 2019) or evidence of being born prematurely (<36 weeks gestation) (Quinn et al., 2016). Neurodivergence is a subcluster within neurodiversity where individuals experience challenges with neurotypical (mainstream) norms and demands.
Resilience	A dynamic process arising from the interaction between an individual and their surrounding contextual factors within the context of adversity whereby individuals show positive adaptation, or better than expected outcomes, despite challenges (Luthar et al., 2000; Luthar et al., 2014; Rutter, 2012).
Risk	Increased likelihood of negative outcomes. Not likelihood of developing neurodivergence/being neurodivergent.
Positive outcome	Functional, mental health, and wellbeing outcomes that are subjectively and/or objectively important for a "good life."

Wehmeier et al., 2010) and experience challenges participating in day-to-day life, limiting engagement in life situations such as employment and education (Black et al., 2019; Blanco-Martínez et al., 2020; Cleaton & Kirby, 2018; Mason et al., 2021; Spencer et al., 2007). Mental health conditions are also particularly prevalent in neurodivergent individuals (Baraskewich & McMorris, 2019), with anxiety, depression, and suicidality being significantly greater than those of the neurotypical population (Baraskewich & McMorris, 2019; Hirvikoski et al., 2016).

A significant body of research has pointed to factors that may place neurodivergent individuals at particular risk for these poor life outcomes. For example, neurodivergent individuals are more likely to have adverse childhood experiences than the general population (Berg et al., 2016), which are known to predict internalizing and externalizing behaviors and physical health conditions (Walker et al., 2022). Conditions including epilepsy, asthma, and a range of other physical conditions are also more common in neurodivergent individuals (Alabaf et al., 2019), which can impact participation and quality of life (Hossny et al., 2017; Strzelczyk et al., 2023). Behaviors associated with developmental conditions such as social-communicative (Isaksson et al., 2019) or executive functioning differences (Zelazo, 2020) and the mismatch between these behaviors and environments designed from neurotypical perspectives may also reduce daily participation, well-being, and quality of life (Frisch & Msall, 2013; Jarl et al., 2019; Krieger et al., 2018; Tobin et al., 2014; Wehmeier et al., 2010). More recent research seeking to examine the applicability of minority stress to autistic adults has further highlighted that stigma (self and external), discrimination, and rejection because of an individual's neurodivergent status can also contribute to unique stressors, having the potential to erode mental health further (Botha & Frost, 2018).

To date, the majority of research and practice in developmental diversity has focused on poor outcomes and risks, neglecting that developmental diversity does not solely result in challenges but is also accompanied by strengths. Strengths such as creativity, the ability to hyper-focus on tasks, visual-spatial skills, in-depth knowledge about specific topics, memory, and particular temperament and personality functions such as trustworthiness, are commonly documented in neurodivergent populations (Armstrong, 2015; Dupuis et al., 2022; Mahdi et al., 2017; Stolte et al., 2022; Von Karolyi et al., 2003). As there is significant variation in individual profiles and developmental pathways, there is also considerable variation in trajectories and life outcomes, and many neurodivergent individuals ultimately live fulfilling lives, even in the face of risk according to subjective and/or objective metrics of a "good life." For example, a meta-analysis revealed that 46.6% of autistic individuals had outcomes that were considered good or fair according to normative standards (Mason et al., 2021). While less explored, others have highlighted that neurodivergent individuals can achieve a "good life" according to subjectively determined criteria (Chapman & Carel, 2022). The notion that developmental diversity brings strengths, as well as challenges, represents a shift away from views of neurodivergent individuals as "disordered" to a neurodiversity paradigm whereby neurodivergence is a "difference" and part of the spectrum of human neurotypes, each with varying ability profiles (Bertilsdotter Rosqvist et al., 2020).

Despite the increasing popularity of the neurodiversity paradigm (den Houting, 2019) and the recognition that many neurodivergent individuals do not have negative outcomes despite risk and adversity, research and practice have mainly remained embedded in biomedical approaches that tend to focus on impairment, deficit, and negative outcome. Limited research has examined strength and positive outcome in developmental diversity, and there is little understanding of why some neurodivergent people thrive, even though they may experience adversity and risk. Resilience refers to the ability to "bounce back" and flourish in the face of adversity (Luthar et al., 2000). Aligning with positive psychology, resilience is concerned with positive outcomes, strengths, and thriving (Luthar et al., 2014). Resilience has historically been conceptualized as a binary trait characteristic: someone is either resilient or not (Wagnild & Young, 1993). However, other conceptualizations of resilience propose a more dimensional view, whereby resilience is a dynamic process arising from the interaction between an individual and their surrounding contexts including factors that can both counter and buffer against the effect of risk, as well as those that promote positive outcomes (Davydov et al., 2010; Egeland et al., 1993; Masten et al., 2021; Ungar & Theron, 2020). Viewing resilience as a process accounts for changes across the life course that may result in the emergence of new strengths but also new risks and challenges. Resultantly, an individual may be resilient at one point in time but not at another point in time or under different circumstances (Luthar et al., 2000).

Conceptualizations of resilience as a process mean that the resilience process is influenced by bio-psycho-social factors and that an individual's resilience across their lifespan is modifiable if factors to building and influencing resilience are identified. Studies in the field of developmental diversity that have examined predictors of outcomes may prove informative in illuminating these factors, and resilience is emerging as an area of interest in the context of neurodevelopmental conditions (e.g. Lai & Szatmari, 2019; Szatmari, 2018). Studies have identified both individual, that is, language and cognitive abilities, emotion regulation, coping strategies, self-perceptions, symptom severity, gender, and race (Bodalski et al., 2019; Bölte & Poustka, 2002; Dvorsky & Langberg, 2016; Kirby et al., 2016; Magiati et al., 2014; Muniandy et al., 2021; Ramos-Olazagasti et al., 2018; Scheffers et al., 2020) and environmental, that is, support and relationships, services and family context (Black et al., 2019; Dvorsky & Langberg, 2016; Kirby et al., 2016; Scheffers et al., 2020) factors that may play important roles in predicting positive outcomes.

Developing a shared understanding of positive functional outcome, the factors contributing to risk and resilience, and how bio-psycho-social factors influence the resilience process, are vital in providing a foundation for work that holistically captures both risks in developmental diversity and positive adaptation. However, capturing the complexities of resilience is challenging, and it is clear that a bio-psycho-social approach is required to adequately describe the factors that contribute to and influence resilience in developmental diversity (Bölte, 2022). The World Health Organization (WHO) International Classification of Functioning (ICF) and its Child and Youth version (World Health Organization, 2007), designed to capture the functioning of developing individuals (i.e. children and youth), provides a bio-psycho-social framework and classification system capable of capturing the complexities of resilience (World Health Organization, 2001). The WHO ICF conceptualizes functioning as the result of the bidirectional interaction between an individual (their body functions and body structures), their activities and participation (execution of tasks and involvement in life situations), their environment (physical, attitudinal, and social environments) and their personal characteristics (e.g. genetics, age, gender, race, ethnicity, and residential status; Grotkamp et al., 2020). It is designed as a complementary framework to the International Classification of Diseases (ICD-11; World Health Organization, 2019), which is concerned with classifying health and health-related diagnoses. In contrast, the ICF is not concerned with diagnostic status and is applicable to all individuals (neurotypical or neurodivergent). The ICF integrates biomedical and social models of disability and enables a focus not only on individual impairment but also on strengths and abilities and environmental impact and responsibilities (Bölte et al., 2021). Through examining body functions and structures, activities and participation, and environmental and personal factors, the ICF is capable of capturing positive functional outcomes and those factors that can predict those positive functional outcomes. The classification system of the ICF contains almost 1700 codes aiming at providing a common language and system for describing functioning and using it as a basis to achieve functional improvements.

Although comprehensive, the ICF classification system has attracted criticism, particularly in clinical applications, because the large number of codes are impractical and lacking in specificity for specific populations seen in clinical practice (Leonardi et al., 2022; Lundälv et al., 2015; Stucki et al., 2002). For this reason, the WHO endorses the development of Core Sets, or sets of codes most relevant to conditions or contexts (Selb et al., 2015). These Core Sets increase the ICF's usability and application in research, policy, and practice and provide a basis for tool and assessment development. Core Sets have been developed to capture factors important for functioning in a range of conditions, including autism (Bölte et al., 2019), attention deficit hyperactivity disorder (ADHD) (Bölte et al., 2018), and cerebral palsy (Noten et al., 2022).

Here, we describe the development of ICF Core Sets for risk and resilience in developmental diversity across ages seeking to provide a roadmap for describing risk and resilience across the life span. Developing Core Sets for risk and resilience in developmental diversity provides the critical first steps for creating evidence-based, standardized tools to assess risk and resilience in neurodivergent individuals. To capture the nuance of resilience, we will examine both positive functional outcomes as well as factors influencing and promoting resilience to risk and negative outcomes. Within the context of this project, it is important to make the distinction that we define risk in regard to an increased likelihood of negative outcomes, not the likelihood of developing or being neurodivergent. Positive outcome is therefore not the lack of a diagnosis but rather encompasses functional, mental health, and well-being outcomes that are subjectively and/or objectively important for a "good life." We refer to both objective metrics of a "good life" as well as subjective evaluations of life outcomes in recognition that normative standards may not be synonymous with a "good life" for neurodivergent individuals (Chapman & Carel, 2021; Lam et al., 2021).

We also refer to both developmental diversity and neurodivergence. Developmental diversity and neurodiversity are both based on the notion that there exist differences in neurodevelopment, and these differences are inherent to the human experience (Armstrong, 2015; Bertilsdotter Rosqvist et al., 2020; Chapman, 2019). Developmental diversity however acknowledges the temporal and contextual dynamics that influence functioning, experiences, and understanding (Hens & Van Goidsenhoven, 2023). This appreciation of temporality aligns with conceptualizations of resilience as a dynamic process across the lifetime. Though developmental diversity acknowledges that natural variation is inherent in human development, there exists a dominant neurotype. In this work, neurodivergence refers to individuals whose development and neurotype diverge from that of the dominant neurotype, including individuals with neurodevelopmental conditions (American Psychiatric Association, 2013; World Health Organization, 2019) or preterm birth (born before 37 weeks of gestation; Quinn et al., 2016).

We intend to contribute to a shift in how developmental diversity is approached in research and practice. Developmental diversity has primarily been viewed through a primarily one-sided focus on risk, impairment, and deficit. By examining positive functional outcomes and factors that influence and promote resilience, we present a more holistic paradigm incorporating resilience, strengths, and opportunities. Notions of resilience and positive psychology coincide with contemporary neurodiversity paradigms (Bertilsdotter Rosqvist et al., 2020; Chapman, 2021; Kapp, 2020; Vanaken, 2022) because they are not concerned with deficits but are instead focused on factors that can be harnessed to promote positive outcomes.

Importantly, we will examine resilience outside of clinical settings across various participation contexts, including education, employment, and leisure domains. We propose that restricting the investigation of resilience to clinical settings acts to perpetuate a purely pathologized approach to developmental diversity whereby a focus is placed on the individual rather than giving equal consideration to how environmental factors may act as barriers or facilitators to functioning. Given that resilience varies across contexts (Luthar et al., 2000), neglecting to examine resilience across life domains may also fail to capture a holistic view of factors important for resilience in developmental diversity, limiting the clinical utility of the Core Sets.

The development method of these Core Sets will broadly align with methods used to develop Core Sets describing factors important for functioning in autism and ADHD (Bölte et al., 2018, 2019). However, past Core Sets have not included personal factors as they are not directly classified as part of the ICF. However, based on previous research in neurotypical and neurodivergent populations, specific factors inherent to a person, that is, their age, gender, socioeconomic status, and worldview, may strongly influence resilience. It, therefore, appears necessary that consideration be given to these personal factors to provide a comprehensive understanding of those factors that promote resilience.

Methods

This research will be guided by a rigorous multi-phase process for developing ICF Core Sets established by WHO and ICF Research Branch (Selb et al., 2015). Phase one consists of four preparatory studies, which will be conducted to identify perspectives on risk and resilience in developmental diversity from multiple viewpoints (researcher, opinion leader, lived experience, and clinical, educational, leisure, and work-life). These preparatory studies will generate candidate categories of ICF and personal factor (Grotkamp et al., 2020) codes relevant to risk and resilience in developmental diversity. In phase two, these candidate categories will subsequently be presented in an international consensus conference to create sets of ICF codes most relevant to capturing functioning and contextual factors pertinent to risk and resilience for developmental diversity.

These Core Sets will be developed as part of a large pan-European project and consortium, Risk and Resilience in Developmental Diversity—Mental Health (R2D2-MH; http://www.r2d2-mh.eu/), which aims to examine resilience as positive adaptation in developmental diversity from biological, cognitive, and psychological perspectives. R2D2-MH comprises experts in their respective fields (i.e. neurodevelopment, biomedicine, genetics, neuroscience) and is overseen by a Scientific Advisory Board and Ethical Advisory Board. Two co-creation reference groups developed for R2D2-MH will also be consulted throughout Core Set development to ensure appropriateness, applicability, and relevance of findings to the developmentally diverse community. These groups include an adult co-creation group comprised of caregivers of neurodivergent individuals and neurodivergent adults, and a young person group of neurodivergent youth (<18 years). Both groups are primarily comprised of autistic people and people with ADHD. The described studies below will comply with the Declaration of Helsinki (World Medical Association, 2013), and ethical approval will be obtained from relevant bodies before their commencement.

Preparatory phase

Systematic review of risk and resilience in developmental diversity (researcher perspective)

Method. A systematic literature review (pre-registration: https://doi.org/10.17605/OSF.IO/Q4YND) will be conducted to conceptualize risk, resilience, and positive outcome in developmental diversity across ages and to synthesize literature examining factors important for promoting resilience. The objectives are to (1) examine how risk, resilience, and positive outcome are conceptualized within the context of developmental diversity, (2) examine the methods and measures used to explore risk and resilience for adverse outcomes in developmental diversity, (3) identify factors that have protective and promotive effects across risk contexts in developmental diversity and (4) identify ICF and personal factor codes relevant to risk and resilience in developmental diversity. The systematic review will be conducted according to the preferred reporting items for systematic reviews (PRISMA) (Page et al., 2021) and will be guided in consultation with researchers as part of the R2D2-MH consortium and the co-creation groups.

The population of interest is neurodivergent individuals. As it was anticipated that there would be limited existing literature examining resilience in neurodevelopmental conditions and prematurity, we expanded our definition to include conditions diagnosed in early childhood that influence functioning for the purposes of this review. Specifically, populations of interest include neurodevelopmental conditions as defined by the DSM-5 (American Psychiatric Association, 2013) and ICD-11 (World Health Organization, 2019), prematurity, chromosome, and genetic conditions and syndromes. The phenomenon of interest is resilience and positive outcome. Included studies will be empirical evidence, overviews, and theoretical papers published in the last 20 years that measure, describe, or focus on resilience in developmental diversity.

Data collection. A comprehensive database search will be conducted to locate eligible articles. A search strategy developed in consultation with experienced university librarians will be used to search multiple databases (i.e. Medline/PubMed, PsycINFO, ERIC, CINAHL) for eligible literature. Search terms will be organized according to condition (e.g. neurodevelopmental disorders, developmental disorder), resilience (e.g. resilience, promotive factors, protective factors), and outcome (positive outcome, optimal outcome). Records identified through the search process will be screened for eligibility at the title and abstract level. Articles retained at the title and abstract level will then undergo screening at a full-text level to determine inclusion.

Data analysis. A data charting framework developed by the research team will be used to support data extraction. The data extraction chart may include study components such as country of origin, population information, study design, outcome measures, and key findings. Key concepts will be identified and extracted from the full-texts and outcome measures and subsequently linked to the ICF and personal factor classification system provided by Grotkamp et al. (2020) in accordance with ICF linking guidelines (Cieza et al., 2019). Absolute and relative frequencies of the outcome measures and the ICF and personal factor categories to which they are linked will be reported.

Expert survey (opinion leader perspective)

Method. An international expert survey will be conducted to gather opinion leader perspectives on the factors they believe are the most relevant to resilience and positive functional outcome in developmental diversity.

Participants. Opinion leaders will include clinicians and professionals (e.g. psychologists, psychiatrists, occupational therapists, speech and language pathologists, physiotherapists, neurologists, pediatricians, social workers, and other professionals with relevant experience) with over five years of experience working with neurodivergent individuals. An internationally diverse sample will be sought to represent each of the six WHO regions (Africa, the Americas, South-East Asia, Eastern Mediterranean, and Western Pacific). A combination of purposive and snowball sampling will be used to identify eligible opinion leaders who will be invited to participate. Eligible individuals will be identified through the R2D2-MH consortium, professional networks, organizations, editorial boards, and other networks. Invited participants will also be asked to identify additional individuals meeting inclusion criteria. Approximately 500 experts will be sought.

Data collection. Upon accepting the invitation to participate, opinion leaders will be sent an online survey comprising three parts. Part one will consist of study information, including confidentiality and consent; part two will collect basic demographic information from participants, such as profession, years of practice, age, gender, and characteristics of the clinical population they have worked with. Part three will contain open-ended questions about the factors they believe are important for risk and resilience in developmental diversity. Questions will be formulated to ensure that each component of the ICF is covered (body functions, body structures, activity and participation, environment, and personal factors) and will be reviewed in consultation with R2D2-MH researchers and reference groups before their use.

Data analysis. Responses to the online survey will be analyzed using a two-phase approach outlined in established guidelines for the analysis of qualitative data using the ICF (Cieza et al., 2019) and as conducted in previous studies (de Schipper et al., 2015, 2016). In phase one, a deductive qualitative content analysis approach will be undertaken to extract meaningful concepts. These extracted concepts will then be linked to the ICF and personal factor classification systems (Grotkamp et al., 2020) according to linking rules outlined by WHO (Cieza et al., 2019). Two independent researchers will complete the linking process to ensure trustworthiness, with any disagreements discussed until consensus is achieved. When consensus cannot be reached, disagreements will be resolved by a third researcher. In accordance with guidelines, an ICF category will be counted once for each expert (Selb et al., 2015). Absolute and relative frequencies of the outcome measures and the ICF and personal factor categories to which they are linked will be reported.

Qualitative study (lived experience perspective)

Method. A qualitative interview study will be conducted to identify aspects of functioning and contextual factors relevant to resilience and positive functional outcome from the lived experience of neurodivergent individuals and those closest to them (i.e. caregivers and those involved in their daily life).

Sample. Participants will include individuals who are neurodivergent (as defined in Table 1), their caregivers, and individuals involved in the daily lives of neurodivergent individuals. Participants from all six WHO regions will be sought, with recruitment occurring through the R2D2-MH consortium, interest organizations, social media, clinics, and other established channels of the research team with a focus on recruiting individuals across ages (children to older adults), sex/gender, ethnicity, and conditions. Data collection will continue until saturation is achieved, which is anticipated to occur with <200 individuals. Saturation will be deemed achieved when no new information is identified from at least two consecutive interviews or focus groups.

Data collection. Focus groups comprising four to eight participants will be conducted. Participants will also be offered the opportunity to engage in one-on-one interviews to accommodate different support needs as required and to account for potential logistical challenges (i.e. participant availability). An interview guide will capture factors that participants believe are the most important for resilience in developmental diversity. The guide will be partly guided by questions proposed for developing ICF Core Sets (Selb et al., 2015) and will be informed by the findings of the systematic review and in consultation with the co-creation groups.

Analysis. Focus groups and interviews will be audio recorded and transcribed verbatim. Interview data will first be analyzed through a deductive qualitative content analysis approach (Krippendorff, 2013). Using this methodology, interview data is examined to extract meanings and concepts within the data, with the ICF providing the guiding framework. Meaningful concepts developed through the content analysis will subsequently be linked to the ICF and personal factor classification systems (Grotkamp et al., 2020). Two independent researchers will conduct the linking process to ensure trustworthiness, with a third researcher involved when consensus between the two researchers cannot be achieved. The absolute and relative frequencies of the ICF and personal factor codes will be reported.

Cross-sectional multicenter study (real-life perspective)

Method. A cross-sectional multi-center survey consisting of interviews, observations, and client record audits will be conducted to identify aspects of functioning and contextual factors relevant to resilience and positive functional outcome in developmental diversity in real-life domains (i.e. clinical setting, education, employment, and leisure).

Sample. Participants will include neurodivergent (as defined in Table 1) children, adolescents, and adults in clinical centers, education settings, social services, and leisure settings (e.g. clubs) across the six WHO regions. Approximately 400 individuals will be sought.

Data collection. Professionals in different settings will be asked to identify eligible clients. Professionals of consenting clients will complete a purposefully adapted version of the ICF Checklist V.2.1a. The ICF Checklist V.2.1a is a checklist of 125 ICF categories covering body functions, body structures, activities and participation, and environmental factors (World Health Organization, 2003). The ICF Checklist will be adapted based on previous Core Set studies (Mahdi et al., 2018a, 2018b), data from the preceding preparatory studies and in consultation with the R2D2-MH consortium and co-creation groups. Adaptations to the rating scales of the ICF Checklist V.2.1a presented in previous studies (Mahdi et al., 2018a, 2018b) will also be utilized. Professionals will rate each body function, body structure, and activity participation item on a quantitative scale ranging from 0–10, where “0” represents no functional disability and “7–10” represents severe functional disability. Environmental items will be rated on a −5 to 5 rating scale where “−5” represents a complete barrier, and “5” represents a complete facilitator. The ICF Checklist also collects demographic and clinical information, including sex, education, and diagnoses. Additional measures of quality of life and resilience will also be taken to enable a comprehensive examination of how functioning as measured by the ICF Checklist may be related to quality of life and resilience.

Data analysis. Descriptive statistics will analyze the ICF checklist, additional measures, and absolute and relative frequencies of ICF, and personal factor codes will be reported.

International consensus conference

Each preparatory study will result in a list of candidate ICF categories important for resilience in developmental diversity from multiple perspectives (research, opinion leader, lived-experience, real-life domains). An international consensus conference will be conducted to refine these codes to establish Core Sets for risk and resilience in developmental diversity. Approximately 30 experts (neurodivergent people or professionals with at least five years of experience working with neurodivergent people) will participate in a three-day international consensus conference. The consensus conference is a rigorous and standardized process following a systematic decision-making framework designed for the development of ICF Core Sets (Selb et al., 2015). Experts will first be familiarized with the ICF, the process of developing Core Sets, and the results of the four preceding studies. An iterative process consisting of working groups and plenary sessions will be undertaken. Experts will be divided into working groups who will engage in multiple sessions to discuss and vote on the inclusion of which ICF codes identified in the preceding studies should be included in the Core Set. Within these working groups, participants will be encouraged to consider and share their expertise and background while presenting arguments for or against the inclusion of particular codes in the Core Set. Between working group sessions, plenary sessions will also be conducted whereby working groups will come together to further discuss ambiguous or undecided codes, or other issues or debates arising (Selb et al., 2015). This iterative process will refine ICF categories to develop sets of ICF codes most relevant to capturing functioning and contextual factors pertinent to resilience in developmental diversity.

Discussion

This protocol describes the process of developing ICF Core Sets for risk and resilience in developmental diversity, providing a comprehensive and holistic guide based on multiple perspectives on positive functional outcome and the factors that are most important to resilience and risk. Given the complexities of resilience and the heterogeneity inherent in developmental diversity, the common language and conceptual basis for understanding resilience and risk in the context of developmental diversity provided by these Core Sets will be of use to researchers, clinicians, services, and policymakers by providing a framework for understanding risk and resilience in developmental diversity and presenting opportunities for the development of tools and supports.

The development of ICF Core Sets for risk and resilience in developmental diversity represents a shift in the way that trajectories and life outcomes for neurodivergent individuals are viewed. Rather than a purely biomedical approach that looks solely at risk, these Core Sets will focus on resilience and positive outcomes. In a climate of person-centered practice, where health professionals are encouraged to view the person holistically (World Health Organization, 2015), focusing solely on risk fundamentally neglects half of a person. By examining resilience alongside risk, these Core Sets will provide a basis for work that holistically captures an individual—not just their risk factors and deficits, facilitating more truly person-centered practices (Bölte, 2022). This shifting view also aligns more closely with ideas of neurodiversity, which suggest that being neurodivergent is more complex than simply having a disease or disorder and is instead a different way of thinking and being that brings with it both challenges and strengths (Chapman, 2019; Kapp et al., 2013). By being concerned with functioning rather than specific diagnoses, the ICF provides the optimal framework for communicating and capturing this viewpoint (Bölte et al., 2021).

A shifting view that focuses not only on risk but also resilience and positive outcomes presents opportunities to pave the way for the development of strength-based approaches to working with neurodivergent individuals. Strengths-based approaches are grounded in positive psychology, which, unlike traditional problem or deficit-focused approaches, focuses on positive experiences and the "optimal life" (Peterson, 2006). Importantly, strengths-based approaches do not ignore an individual's challenges but instead examine the strengths, abilities, resources, and assets held by an individual that may be utilized to overcome these challenges (Saleeby, 2006). The Core Sets developed in this body of work will provide a list of factors most important to promoting resilience and positive outcomes in developmental diversity. These factors may provide a starting template for developing tools, and measures that seek to identify the strengths and assets held by an individual. The Core Sets can be operationalized into checklists, clinical interviews, or other assessment methods to identify assets and strengths of an individual.

In addition to being operationalized into tools and measures, the Core Sets may provide some direction for newly developed interventions for promoting resilience and harnessing an individual's strengths and assets to promote positive outcomes. Some strides have been made regarding the use of strengths-based approaches in conditions such as autism. Still, this work has largely been restricted to education and employment contexts, primarily because autistic individuals often demonstrate strengths in the technology field (Jones et al., 2018; 2022; Lee et al., 2019). The factors important for promoting and influencing resilience identified by the development of these Core Sets may provide avenues for a broader view of the strengths and assets that could potentially be leveraged during intervention to promote resilience. In particular, the ICF is not only concerned with the components of an individual and how they influence functioning, but it also recognizes the role the environment may play (World Health Organization, 2001). ICF Core Sets for risk and resilience in developmental diversity may identify environmental factors (i.e. attitudinal, physical, social) that could become intervention targets for promoting resilience and positive outcomes rather than focusing solely on the individual. Prior to the Core Sets being used to inform assessment, intervention, and support, they will require validation to ensure that categories included in the Core Sets capture the entirety of factors important for resilience across the breadth of neurodivergence, and to determine their utility and applicability across a range of contexts. Validation for previously developed Core Sets have revealed good results, often with greater than 80% coverage (Black et al., 2019; Fridell et al., 2022; Viljoen et al., 2019).

This project will capture both positive functional outcomes, as well as the factors predicting these outcomes. While the ICF framework acknowledges that functioning is the result of the bidirectional interaction between body functions and structures, activities and participation, and contexts, we propose that similar interactions may be observed not only between components, but also *within* components when examining outcomes alongside predictive and promotive factors (Figure 1). For example, having relationships with friends (activities and participation) may be a desired functional outcome, however, this factor may also be important in predicting or promoting other positive functional outcomes such as participation in employment (activities and participation). In this way, participation may predict participation. We anticipate that this interaction between outcomes and predictive and promotive factors may differ along the developmental trajectory. For instance, among younger children body functions (e.g., language abilities) may be important in promoting relationship development (activities and participation), however in older populations, it is possible that environmental and activity and participation factors may play a more important role in predicting positive functional outcomes. The ICF will enable the nuances of these relationships to be explored.

Exploration of factors important for resilience across contexts and domains of everyday life will provide insights into how environmental factors may support or hinder resilience and positive outcomes. Examining factors beyond the individual, including the social, physical, and attitudinal environment, is particularly important within the context of developmental diversity, where research consistently demonstrates the influential role environmental factors have on facilitating and hindering function (de Schipper et al., 2016; Mahdi et al., 2017, 2018a, 2018b). In fact, emerging research has shown that in some contexts, functional challenges of developmentally diverse individuals are essentially remediated. For example, autistic and non-autistic adults are equally effective in communicating information within their own neurotypes (Crompton et al., 2020).

Finally, though resilience is increasingly of interest in the disability field, there remains little known about how resilience is conceptualized within the context of developmental diversity, and there is a limited understanding of the factors that most support resilience and positive outcomes in this population. The evidence generated in the preparatory phases (systematic review, international survey, qualitative study, multi-center study) will contribute significantly to the limited body of research examining resilience in developmental diversity, providing opportunities for future research.

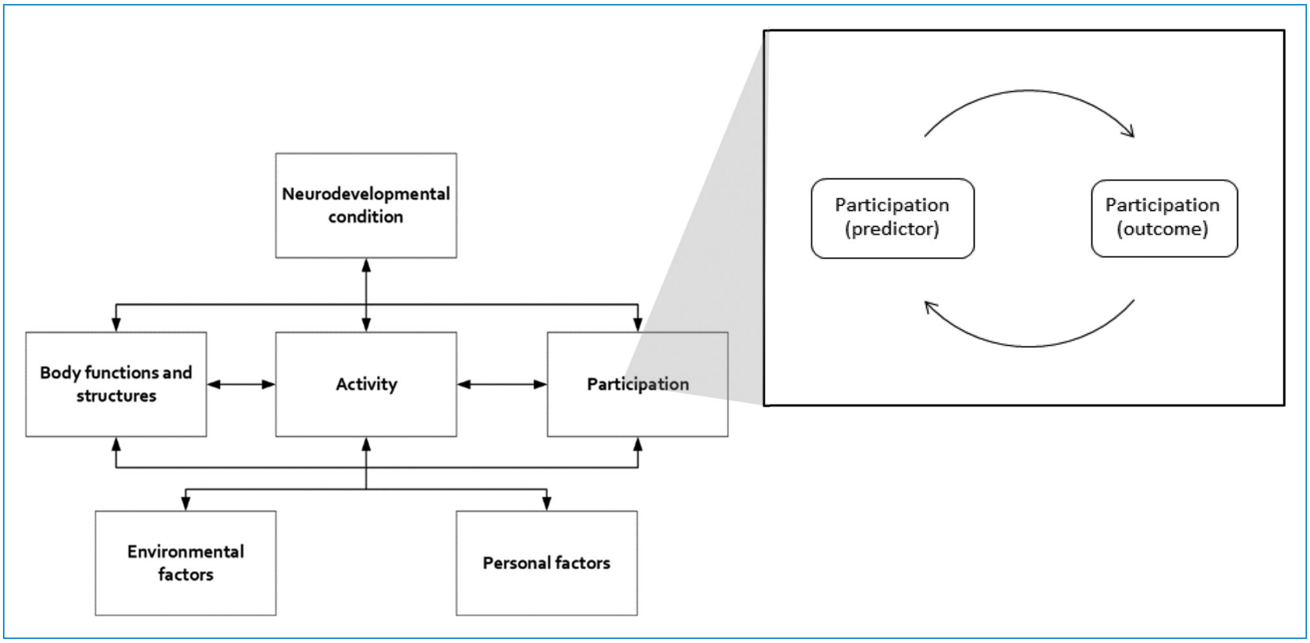

Figure 1. Representation of the ICF and potential within domain interaction.

Challenges

Developing ICF Core Sets for risk and resilience in developmental diversity will not be without challenges. First, resilience is a complex process that can differ between and within individuals across the lifespan (Davydov et al., 2010; Ungar & Theron, 2020). Therefore, the factors important to resilience are likely to also vary across the lifespan. This is further complicated by the heterogeneity inherent in developmental diversity and the fact that the nature and impact of characteristics can change across the life course (American Psychiatric Association, 2013). Developing Core Sets that adequately capture those factors that predict and promote resilience and positive outcomes for all neurodivergent individuals across the lifespan may be challenging. The preparatory studies will investigate how factors important for resilience may vary across the life course and how life transitions (i.e. starting school, starting work) may influence an individual's resilience. These preparatory studies will provide insight into whether specific life stage Core Sets are required. We envision that two Core Sets may be required, an early life to school years and a lifetime Core Set.

Given the heterogeneity inherent in neurodivergence, a potential criticism that may arise is that developing Core Sets for risk and resilience for all neurodivergent individuals would obscure resilience factors that may be particularly important for certain neurodivergent populations but not others. For example, sociability is a commonly observed strength of individuals with Down Syndrome (Dykens, 2007; Nygaard et al., 2002), while visual-spatial abilities are more commonly observed strengths in autistic individuals (Mottron et al., 2006). In response, we argue that the ICF by design is not concerned with diagnostic labels and is instead etiologically neutral and universal. It does not seek to differentiate between health conditions, acknowledging that an individual's functioning cannot be determined based on their diagnosis, or lack thereof, alone (World Health Organization, 2001). For this reason, we believe that developing Core Sets for developmental diversity, incorporating a broad range of conditions, aligns with the ICF's underlying principles and intended purpose. Additionally, there has been more recent recognition that discrete diagnostic categories may insufficiently reflect the true nature of neurodevelopmental conditions given their considerable overlap and heterogeneity (Astle et al., 2022). The development of Core Sets spanning neurodivergence thus also aligns with calls for more transdiagnostic approaches (Astle et al., 2022).

Unlike other Core Sets, these ICF Core Sets seek to include personal factor codes. The ICF does not classify these personal factors due to the variability across contexts. However, it was deemed necessary to include personal factors as neglecting to do so may exclude factors of fundamental importance to risk and resilience in developmental diversity. The classification of personal factors has received some criticism, which will be necessary to consider in developing these Core Sets. The WHO does not provide a formal classification system contributing to ambiguity and inconsistency in its application (Simeonsson et al., 2014). Some classification systems have been developed by others, such as those by Geyh et al. (2019) and Grotkamp et al. (2020). The Grotkamp classification system was selected for this Core Set development because they present a more comprehensive classification (Karhula et al., 2021). Relatedly, there may be ambiguity as to what constitutes a personal factor (Simeonsson et al., 2014), and there is overlap between those considered "personal" and those coded in the ICF (Grotkamp et al., 2020). For example, functions involved in memory can be coded as mnestic factors in the Grotkamp classification system or as a body function in the ICF. The research team will follow a rigorous decision-making process to improve consistency in applying personal factors. Any factor that may be considered a personal factor will first be evaluated to determine whether it is part of the health condition or not. For example, memory functions may be coded as a body function rather than a personal factor due to several developmental conditions influencing this function. A personal factor code may also be applied when no other relevant code within the ICF exists. A final criticism worthy of mention is the potential for the description of personal factors negatively influencing function to "blame the victim" (Simeonsson et al., 2014). Indeed, based on previous literature, certain personal factors such as socioeconomic status may play a role in the risk of poor outcomes (Freeman et al., 2016). However, the focus of the development of Core Sets is to describe those factors that may contribute to risk or resilience, focusing on factors that contribute to positive outcomes. The research team will be required to engage continuously with these criticisms of personal factors to ensure their most appropriate application in the Core Sets.

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