Positive Psychology and Disability Series

Series Editors: Michael L. Wehmeyer · Karrie A. Shogren

Roger J. Stancliffe
Michael L. Wehmeyer
Karrie A. Shogren
Brian H. Abery *Editors*

Choice, Preference, and Disability

Promoting Self-Determination Across the Lifespan

Springer

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Michael L. Wehmeyer, Beach Center on Disability, University of Kansas, Lawrence, KS, USA
Karrie A. Shogren, Kansas University Center on Developmental Disabilities, University of Kansas, Lawrence, KS, USA

The **Positive Psychology and Disability** book series provides comprehensive coverage of research and practice issues pertaining to the application of constructs and principles from the discipline of positive psychology across the disability context. In addition, books in the series address the application of strengths-based approaches to understanding disability and designing and implementing supports to enable people with disabilities to live, learn, work, and play as meaningful participants in their communities. Drawing from traditional areas of focus in positive psychology, series books:

- Provide cutting-edge research and practice that can improve the quality of life and well-being of people with disabilities.
- Address theory and research across such areas as hope, optimism, self-determination, and character strengths.
- Examine research- and evidence-based practices to promote involvement in goal setting, problem solving, and decision making.
- Synthesize research and practice from multiple disciplines and apply strengths-based approaches to disability.

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This book is dedicated to self-advocates with disability and their efforts to exercise their basic human right to self-determination. Through advocating both within and outside of existing systems to demand their personal self-determination and enhance the choices available to others, they are making their voices heard around the world. They inspire us to do more, aim higher, and work to eliminate structural discrimination and systemic oppression.

Foreword

> A decent society is one whose institutions do not humiliate people. A civilized society is one whose members do not humiliate one another. – Avishai Margalit

> And yet, there is a solitude, which each and every one of us has always carried with him more inaccessible than the ice-cold mountains, more profound than the midnight sea; the solitude of self… Such is individual life. Who, I ask you, can take, dare take, on himself the rights, the duties, the responsibilities of another human soul? – Elizabeth Cady Stanton

It is commonplace in this century for family members of people with complex disabilities to say that living with disability opened their minds in ways they had never anticipated. That has been my experience over the last 36 years as a parent, advocate, advocacy organization leader, government official, and now president of Inclusion International. The doorway to the deepest thinking about human rights – and about all that makes us human – is opened wide by the old mistakes and new problems, the persistent paradoxes and changing issues that surround us. People with disabilities themselves often lead the way. The authors whose contributions appear in this volume have thought deeply about the questions that often confound us, whether we are politicians, mothers, or disabled advocates. A central question, in my experience, is how to support the individual freedom of persons with intellectual, cognitive, or complex cognitive disabilities.

We live in times when more people with more complex disabilities can be supported longer and better in families and communities than was ever possible in the past centuries. Then, resources, tools, and even ideas were scarce. Now, we have better systems, better technologies, and better expectations. We continue to develop better ideas, often in response to cultural shifts.

Thinking about self-determination is ever more challenging as proponents of neoliberal thought attempt to extend its reach in the world. Clearly, it is worth pursuing the idea that disabled persons can be in charge of their own destiny, but the overemphasis on individual control and personal responsibility can be isolating, illogical, and damaging. The idea that the person alone is responsible for their choices and their outcomes is laughable for families who see clearly that despite abstract theoretic doctrines, the practicable options available are often severely limited by systems, cultures, communities, and policies based on long-held ideas of scarce resources and even by family circumstances. Systems can be disabling, sometimes more than impairments are disabling. Economies and cultures can destroy capabilities or provide no opportunities for exercising atypical capacities. Alas, families and loved ones sometimes can be disabling, too.

I have been responsible for systems and have had shared responsibility for a family. We do the best we can. Sometimes we fail. Often, our reach exceeds our grasp. We are always grateful when our best researchers and thinkers take on the bigger questions, as the authors of these chapters have done.

One error most of us make, especially when we are failing or when systems fail us, is to believe that our own city, state, or nation is unlike any other and that all of our problems can be solved by political action and policy initiatives within our own systems. These authors have addressed the problems and opportunities of freedom, choice, and self-determination around the world, giving us a rare opportunity to think globally and from a human and plural perspective.

The Universal Declaration of Human Rights (UDHR) as reflected in its Conventions has become a touchstone that many working on problems associated with human disability use to test proposals and guide joint inquiry and activism. The process by which scholars from around the world drafted the Declaration deserves to be better known than it is. It did not involve first agreeing on a common scientific or philosophic or cultural doctrine as the basis of human rights; rather, the participants sought and found common grounds of human rights, enumeration of particular rights, and agreement on the actions required to achieve and protect them. The plurality of research approaches and views in this volume reflect that approach.

Another error that is often repeated, but not here, is to hold that the ultimate goal of self-determination is to control financial resources. The focus on control of resources can nudge us toward greed. As the famous self-advocacy battle cry “Nothing about us without us” morphs into “Nothing about me without me,” it leaves social responsibility in the dust. In my own country, problems caused by the inequitable distribution of wealth seem to be mirrored in the inequitable distribution of human services. The neolibertarians who would reorder our world into a gilded age on steroids seldom acknowledge that not everything is about money and regulation. Disabled people and their families – even young children – are now serving as one of the last and most powerful political and cultural reminders that we owe something to one another.

That is one of the most important lessons one learns when living with disability: dignity is about much more than money and regulation. Freedom from external control or limitations is only part of liberty; the other and probably more important part is to be free of internal errors such as greed, avarice, or ignorance that can cause one to make choices that will ultimately bring harm to oneself or others. Thus, greedy people are never free, even if they are wealthy beyond measure. Access to education is one of the positive contributions society can make to the individual capabilities that support liberty, and inclusive education provides the benefit of helping students with and without disabilities in their attainment of genuine positive liberty.

I have often noticed that ideas and technologies first developed to aid people with intellectual disabilities end up being useful to all of humanity. As we react to cultural shifts, sometimes we cause them, too. It does not escape my notice that we need much better understanding of choice, preference, and self-determination and how to support them in many aspects of human life and endeavor as we continue to balance on the razor's edge of both climate and economic disaster. Perhaps humanity is showing signs of some new form of collective intellectual disability when it comes to addressing climate and economic collapse. Perhaps ideas here will help.

If "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world" [UDHR, preamble], then we have work to do together. The Convention on the Rights of Persons with Disabilities is helping us understand the Sustainable Development Goals, and vice versa. Families and policymakers in cultures around the world are wrestling now with the connections among freedom, choice, and disability. All cultural views are welcome to the discussion, if we hold to no insistence that only one view can be correct. Experts in all scientific, practical, and artistic disciplines can contribute, as the authors here are doing.

Sue Swenson, MBA, is the current President of Inclusion International, a global network of persons with IDD and their families who work to advance the rights and inclusion of persons with intellectual disabilities in all parts of the world. Prior to her association with Inclusion International, she served as the Deputy Assistant Secretary for the Office of Special Education and Rehabilitative Services (OSERS) at the US Department of Education during the recent Obama Administration. In this capacity, she advised the US Secretary of Education on matters related to the education of children and youth with disabilities, as well as employment and community living for youth and adults with disabilities. Prior to assuming her responsibilities at the OSERS, she served in the Clinton Administration as the Commissioner for Developmental Disabilities in the US Department of Health and Human Services as well as Executive Director of the Joseph P. Kennedy Jr. Foundation and CEO of The Arc of the United States. She became involved with disability advocacy because her middle son, Charlie, had profound disabilities. She was active in the Minneapolis, Minnesota, public schools as well as in state and federal policy while working as a Professional Services Marketing Director before being named a Kennedy Fellow in the US Senate in 1996. Sue earned her AM at the University of Chicago as well as an MBA at the University of Minnesota.

Bethesda, MD, USA
Sue Swenson

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Michael L. Wehmeyer, PhD is the Ross and Marianna Beach Distinguished Professor in Special Education and Chair, Department of Special Education, University of Kansas. He is also Director and Senior Scientist at the Beach Center on Disability, also at KU. His research focuses on issues pertaining to self-determination, the application of positive psychology to the disability context, applied cognitive technologies, and the education of learners with intellectual disability and extensive support needs. He is a Fellow of the American Psychological Association (Division on Intellectual and Developmental Disabilities), the International Association for the Scientific Study of Intellectual and Developmental Disabilities, and the American Association on Intellectual and Developmental Disabilities, the latter of which he is also a Past President. He is currently the President of the Council for Exceptional Children's Division on Autism and Developmental Disabilities.

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About the Contributors

Lynda Lahti Anderson, PhD, MPH is a Research Associate at the University of Minnesota's Institute on Community Integration. She holds a PhD in Rehabilitation Science with a focus on self-management of disability and chronic conditions as well as master's degrees in public health and health administration. She has extensive experience managing residential programs, working with families in home and school settings, and as a Case Manager for recipients of home- and community-based services. Her research interests include qualitative and mixed methods research as well as analysis of disability-focused secondary datasets. Her work at the University of Minnesota includes refinement of national survey (FINDS) on the experiences of family caregivers, secondary data analyses and data briefs related to family caregiver outcomes, and serving as Project Director for a Family Information Systems Project.

Marjorie Aunos, PhD is an internationally renowned Researcher, Adjunct Professor at two Canadian universities, and Clinical Psychologist. She was a Director of Professional Services within a health and social service agency in Montreal, Canada, and founded an evidence-based program for parents with an intellectual disability that is nationally recognized and deemed as best and promising practice by Accreditation Canada. She is also the Chair of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Special Interest Research Group on Parents and Parenting with Intellectual Disabilities (SIRG/PID) and has led a number of book chapters and presented at national and international conferences. She was a Coeditor of a double special issue of the *Journal of Applied Research in Intellectual Disabilities* and has published many and various peer-reviewed manuscripts.

Christine Bigby, PhD, FIASSIDD is Professor and Director of the Living with Disability Research Centre at La Trobe University, Melbourne, Australia. She has a long track record of working in partnership with disability support organizations investigating the effectiveness of social programs and policies that aim to support the social inclusion of adults and older people with intellectual disability. She has won the Research Prize of the Australasian Society for Intellectual Disability three times since 1993. She is a Member of the College of Experts of the Australian Research Council and has published 6 books, 35 book chapters, over 135 journal articles, and numerous research reports. She is Founding Editor of the journal *Research and Practice in Intellectual and Developmental Disabilities* (RAPIDD) and was Editor of *Australian Social Work* from 2008 to 2013.

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Nicholas P. Cocchiarella, BA is a strong advocate for equality among all humans, no matter the shape of our bodies and minds. He graduated from the University of St. Thomas in 2014 with a degree in communications and journalism and is planning on furthering his education in the area of vocational rehabilitation. His interests include long walks through nature, nerding out over Harry Potter, and enjoying craft beer.

Bernadette Curryer, MHlthSc (Dev Disability) is currently a PhD Candidate at The University of Sydney, researching self-determination of adults with intellectual disability within the context of family relationships. Beginning her career as a Registered Nurse, she later moved into the disability sector and worked primarily in the fields of advocacy and adult education. As a Board Director of the Australasian Society for Intellectual Disability, she is actively involved in the promotion of quality practice through research dissemination. These professional roles, together with her experience of parenting an adult daughter with an intellectual disability, have resulted in a strong belief in the right of people with disability to live a life of choice, purpose, and inclusion.

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Marja W. Hodes, PhD is Clinical Psychologist and Head of the Psychologists of the Dutch service organization ASVZ, Department of Family Services. She has worked for the past 35 years with families headed by parents with intellectual disabilities. Together with her colleagues, she developed the toolkit "Talking About Children." This toolkit supports future parents with intellectual disabilities to think carefully about the consequences of having and raising a child. In 2010, she won a national award for this toolkit. With the money from this award, she built a website with free downloadable tools to support future parents. In addition to her clinical work, in 2008, she started scientific research concerning parenting by parents with intellectual disabilities at the VU Amsterdam. She developed the Video-Feedback Intervention to Promote Positive Parenting for Parents with Learning Difficulties (VIPP-LD) with a focus on harmonious parent-child interactions and sensitive discipline.

Berit Höglund is a Registered Nurse and Midwife in Sweden. For nearly 30 years, she worked as a Midwife at the delivery ward, in antenatal care, and with family planning. In the 1990s, she became interested in midwifery care for women with intellectual disability. In the early 2000s, she received a masters' degree in medical science, which led to her further studies. She completed her doctoral studies in 2012 at the Department of Women's and Children's Health at Uppsala University, Sweden. The overall aim of her thesis was to investigate pregnancy and childbirth in women with intellectual disability and the health of their newborns in Sweden. Her postdoctoral studies have focused among other things on the health of preschool children born to women with intellectual disability and on contraception in women with intellectual disability.

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Laurie Kincade, MA is a Doctoral Candidate in the School Psychology PhD Program at the University of Minnesota. She has worked for nearly 4 years as a Graduate Assistant at the Institute on Community Integration with research focusing on the importance of self-determination for individuals with disabilities. She has also assisted on projects focusing on smart home technology, reading assessments, and implementation science. She has coauthored publications in these areas and is currently working on two other manuscripts. Her own research interests include the importance of student-teacher relationships and social-emotional learning programs and practices at a universal and school- and class-wide level. She has deep passion for diversity and equity within all of her work.

Dušan Klapko, PhD has been a Faculty Member at the Department of Social Pedagogy at Masaryk University in Brno, Czech Republic, since 2005. In his teaching, he focuses on social theories, social inclusion, history of social pedagogy, as well as methodological approaches and courses in experiential pedagogy. In his research, he analyzes textbooks, power discourses in the area of socialization of Roma children, and the impact of theater on education and experiential learning. His most notable accomplishments include the completion of two large-scale projects focused on the education and opportunities for social inclusion of Roma students and a project of the National Heritage Institute of the Czech Republic for which he received the Europa Nostra Award.

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Part I
Overview of Choice and Preference

Choice Availability and People with Intellectual Disability

Roger J. Stancliffe

This chapter begins with a reflection on the range of reasons why choice is important. Definitions of choice are considered next, including examination of common misunderstandings of choice. Next, I describe and analyse major assessments of choice availability, with attention to assessment involving self-reported choice versus choices reported by proxies. This section is followed by an examination of the major research findings concerning choice availability for adults with intellectual disability. This chapter also engages with the under-researched topic of choice within various types of relationships. Implementing choices with and without support is considered in the context of the implicit tension between autonomy-as-independence and autonomy-as-volition (see chapter "The Development of Choice-Making and Implications for Promoting Choice and Autonomy for Children and Youth with Intellectual and Developmental Disabilities"). This chapter concludes with a brief examination of 'what works': interventions that purport to enhance choice availability. A number of the issues canvassed are examined in more detail in other chapters of the book, so where appropriate, reference is made to the relevant chapters.

Why Is Choice Important?

There are multiple reasons why choice is particularly important for and to people with intellectual disability. First, people with disabilities themselves have stated repeatedly that they want to control their own lives (Miller, Cooper, Cook, & Petch, 2008). As New Zealand self-advocate Robert Martin put it, 'We want to live in a community that encourages us to learn about decision-making and to take

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responsibility for our own decisions. Until this happens, true empowerment and self-determination can only be a dream' (Martin, 2006, p. 127). This issue is taken up in depth in the chapter "Reflections on Choice: The Stories of Self-Advocates" of this volume which reports the views of prominent US self-advocates about choice.

Second, there is a problem of restricted availability of choice to people with intellectual disability compared to the general community. Research shows people with intellectual disability make far fewer choices (Sheppard-Jones, Prout, & Kleinert, 2005; Wehmeyer & Abery, 2013).

Third, because of these issues, choice and self-determination have become prominent features of national legislation and policy in many countries. For example, in the chapter "Choice, Control and Individual Funding: The Australian National Disability Insurance Scheme", Laragy and Fisher discuss Australia's *National Disability Insurance Scheme,* which is designed with choice and control by people with a disability as fundamental and explicit design principles. Xu and his co-authors in the chapter "Choices and Transition from School to Adult Life: Experiences in China" comment that self-determination and choice for people with disability are relatively new concepts in China, but also note that these ideas are beginning to appear in school curricula, suggesting a more positive climate may be developing. By contrast, recent changes in regulations that limit support available to Norwegians with intellectual disability for choosing integrated employment are examined by Tøssebro and Olsen in the chapter "Employment Opportunities for People with Intellectual Disabilities".

Fourth, choice is central to the Convention on the Rights of Persons with Disabilities (United Nations [UN], 2006), where choice is identified as a human right. For example, Article 19 states that 'Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others'. However, Tichá and her co-authors in the chapter "Choices, Preferences and Disability: A View from Central and Eastern Europe" discuss the numerous attitudinal, service-provision and policy barriers that continue to substantially constrain choice by people with intellectual disability in Central and Eastern Europe, despite many countries there having signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006).

Fifth, self-determination and choice comprise a fundamental domain of quality of life (QOL) (Schalock, Verdugo, Gomez, & Reinders, 2016). For example, Neely-Barnes, Marcenko and Weber (2008) showed empirically that exercising more choice was positively related to better QOL outcomes for other QOL factors such as rights, community inclusion and relationships.

Sixth, having choice has positive effects on other outcomes. For example, choice improves activity engagement and reduces challenging behaviours (Tullis et al., 2011; Zelinsky & Shadish, 2018; the chapter "Preference Assessments, Choice, and Quality of Life for People with Significant Disabilities" of this book by Cannella-Malone & Sabielny).

What Is Choice?

A number of similar definitions of choice have been proposed in the intellectual disability literature. Stancliffe (2001) reviewed earlier definitions of choice and identified elements such as (a) actively making a choice based on one's preference and not passively accepting decisions made by others, (b) selection from a minimum of two options and (c) free choice without coercion. Based on these three components, Stancliffe proposed the following definition: 'making an unforced selection of a preferred alternative from two or more options' (Stancliffe, 2001, p. 92). This definition appears compatible with more recent definitions such as 'choice-making requires that a person … can choose without coercion, and can express a preference to others' (Wehmeyer, 2007, p. 19).

Choices take place in a context, and appropriate environmental conditions are necessary to access, make and communicate choices. As described by Cannella-Malone and Sabielny in the chapter "Preference Assessments, Choice, and Quality of Life for People with Significant Disabilities", for people with significant disabilities and limited communication repertoires, opportunities for choice may require the support person to present alternatives carefully and to respond to selection methods, such as eye gaze, used by the person to communicate preferences. These authors also emphasise the importance of routinely incorporating many opportunities for choice throughout the day.

In addition to the immediate here-and-now context, developmental factors underpin choice. As Wehmeyer and Shogren point out in their chapter "The Development of Choice-Making and Implications for Promoting Choice and Autonomy for Children and Youth with Intellectual and Developmental Disabilities", making and communicating selections in childhood, and experiencing the consequences of these choices, provides the foundation for more complex choice and decision making in later life.

Stancliffe's (2001) definition describes minimum requirements for choice to exist, but there are other factors at play when considering more fully developed choice. Ideally, there would be many more than two options, and the individual would generate the options, rather than someone else controlling the available alternatives. Choice between two or more unattractive options is often viewed as a dilemma rather than a real choice. For example, one's day activity options being restricted to sheltered employment, unpaid day activities at a disability centre or having no structured daytime activity may all be unattractive to a person who is seeking a fully paid job in the mainstream workforce. However, as noted in the chapter "Employment Opportunities for People with Intellectual Disabilities" on employment, a key consideration is the individual's appraisal of the options. If one or more of these options are considered valued and attractive, then the person has a real choice.

In addition, there is an important distinction between making a choice and implementing it. Wehmeyer and Shogren in their chapter "The Development of Choice-Making and Implications for Promoting Choice and Autonomy for Children and

Youth with Intellectual and Developmental Disabilities" propose the concept of *autonomy-as-volition*. This approach focuses on the person *making* their own choice with *implementation* of the choice involving whatever support is needed.

Misunderstandings about choice A misguided interpretation of choice has sometimes been used to try to justify poor support of people with intellectual disability. For example, some may see a person with intellectual disability spending large amounts of time doing nothing (euphemistically described as *relaxing*) as an active choice and an indication of a preference for inactivity. Logically, a preference for inactivity requires evidence that the person rejects activity alternatives and opts to do nothing, that the activity offered is known to be enjoyed by the person and that appropriate support for participation is provided. By contrast, an approach called *Active Support* 'assumes that people with severe ID are disengaged not through their own active choice, but because the assistance needed to participate is unavailable' (Stancliffe, Jones, Mansell & Lowe, 2008, p. 209). Active Support is a well-developed approach that involves carefully structured support for participation in chosen activities and is particularly relevant to people with more severe disability who may not be able to initiate a desired activity without support.

Brown and Brown (2009) commented on another misunderstanding of choice which proposes that people with intellectual disability should choose anything they like, with any unpleasant consequences simply seen as an unavoidable result of the choice made. This approach overlooks the possibility that the person is making an uninformed choice, unaware of some negative outcomes. Brown and Brown proposed an educative approach, whereby the person is supported to think through the consequences and given the opportunity to change their mind or to experience and learn from the consequences if they proceed with their choice. van Hooren, Widdershoven, van den Borne and Curfs (2002) described a similar joint learning approach as a means of dealing with the ethical dilemma of managing risk and preserving choice.

Assessing Choice Availability

As noted elsewhere in this chapter, fundamental research findings include (a) that people with intellectual disability have access to fewer choices than their peers and (b) that other people either make the choice for the person or provide the person with restricted choice or limited control. Therefore, major objectives of policy and practice are to increase access to choice and to enhance the person's level of control over the outcomes of these choices. Having assessments that can provide information on these issues is necessary to document, understand and change these restricted opportunities. The assessments examined in this section have largely been developed to assess these dimensions of choice making – availability of choice and control over choices.

Assessment methods for identifying specific individual preferences (e.g. preferring tea to coffee or hot chocolate) have also been the focus of considerable research attention, especially relating to individuals who are unable to state their preferences. These issues of preference assessment are examined in the chapter "Preference Assessments, Choice, and Quality of Life for People with Significant Disabilities" of this book and will not be considered in the present chapter. Other aspects of choice assessment, such as measuring the steps involved in making choices or identifying the sources of support for choice making, have received much less attention from researchers developing choice assessments. One likely reason for this approach is that these other factors tend to be moot if the choice is not available to the person.

Stancliffe (2001, Table 1) listed four scales designed to assess choices available to people with intellectual disability (Kearney, Durand, & Mindell, 1995; Kishi, Teelucksingh,, Zollers, & Meyer, 1988; Schalock & Keith, 1993; Stancliffe & Parmenter, 1999). More recently, O'Donovan et al. (2017, Table 1) described eight scales. Table 1 below is a revised and expanded version of Stancliffe's (2001) Table 1. It does not claim to be comprehensive listing of every available scale. To help readers who seek access to the item content of the scales listed in Table 1, the studies which include full information about scale item wording and scoring are identified with a superscript 'a' in the second column.

Item content Very large numbers of choices are potentially available to people every day. A comprehensive listing would generate unwieldy and impractical assessment tools. Instead, the available assessment tools listed in Table 1 each include items on a limited selection of choices (ranging from 3 to 26 items) intended to serve as indicators of choice availability more generally. This approach to content selection requires items that are applicable to most people and representative of choices more generally. This selection issue has been dealt with by:

- Choosing item content related to choice within activities that most people engage with often (e.g. what to eat, when to go to bed, leisure activities) so as to minimise missing data due to non-applicable items and to capture the person's typical level of control because the item involves a choice that occurs very regularly
- Framing questions to relate to broader choice issues not specific options, such as 'Who decides your daily schedule [like when to get up, when to eat, when to go to sleep]?' (Lakin et al., 2008, p. 330)

It is notable that there is similarity in the item content of a number of the scales listed in Table 1. One reason is that new scales have often borrowed or adapted items from earlier assessments. For example, the choice items used by Kishi et al. (1988) provided most of the items in the scales examined by Heller et al. (2000) and by O'Donovan et al. (2017). O'Donovan et al. (p. 475, parenthetical material added) also noted that 'of the 9 items in the NCI scales (used by Lakin et al., 2008 and Tichá et al., 2012), 6 of these items are included in the adapted Heller et al. (2000) used in this study'. The scales set out in Table 1 mostly focus on residential, community and leisure issues, with limited attention to other settings. One exception is the scale used by Agran, Storey and Krupp (2010) which examines choices at work.

Table 1 Scales assessing choice

Scale	Authors	Item content	Respondent (self or proxy)	Response scale
Life Choices Survey	Kishi et al. (1988)[a]	11-item scale (including a 'lie' item)	Self-report or proxy	5-point Likert scale ranging from choice *not available/ appropriate to me* to *I can make this choice when I want to*
Resident Choice Assessment Scale	Kearney et al. (1995)	25-item scale about adults	Proxies (direct-care staff)	7-point Likert scale ranging from *Never* to *Always*
Quality of Life Questionnaire – Empowerment factor	Schalock and Keith (1993)[b]	10-item scale about choices and control over one's life	Self-report or completed by two proxies	3-point scale – item-specific options, each ranging from free choice to very little/no choice
Choice Questionnaire	Stancliffe and Parmenter (1999)[a]	26-item scale dealing with a variety of choices for adults	Self-report or proxy	3-point scale – item-specific options, each ranging from free choice to others decide/I am not allowed
Daily Choice Inventory Scale	Heller, Miller, Hsieh and Sterns (2000)[a]	12 items	Proxy	2-point scale – choice made by self; others
The Resident Choice Scale	Hatton, Emerson and Robertson (2004)[a]	26-item scale on opportunities for choice in residential settings	Proxy	4-point scale: No supports/ opportunities for choice; Little real choice; expresses preference but does not have final say; Person's expressed preference is the final say
Everyday Choice Scale Support-Related Choice Scale	Lakin et al. (2008)[a] Tichá et al. (2012)[a]	3 items (everyday choice) and 6 items (support-related choice) from the *National Core Indicators Adult Consumer Survey*	Self-report or proxy	3 response options: person chooses; person has help choosing/has some input/can request a change; someone else chooses
Unnamed scale	Agran, Storey and Krupp (2010)	6-item scale about the availability of choices and support for choice making at work	Self-report	2-point (yes/no)
		7-item scale about work-related choices (a) made today and (b) usually made	Self-report	2-point (yes/no)

(continued)