



2011

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Recommended Citation

Genchanok, Anna and Kunce, Linda, "Explanatory Autism Disclosure in the Workplace: Perspectives of Key Stakeholder Groups" (2011). *Honors Projects*. Paper 144.
http://digitalcommons.iwu.edu/psych_honproj/144

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Explanatory Autism Disclosure in the Workplace: Perspectives of Key Stakeholder Groups

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Abstract

The high prevalence of unemployment and underemployment among adults with Autism Spectrum Disorders (ASD) is exacerbated by public misunderstanding of this complex condition. Many individuals with ASD work alongside coworkers and supervisors who are unknowledgeable about the disorder, which promotes the development of misconceptions regarding the individual's ability to function in the workplace. Despite frequent recommendations both for and against the use of explanatory ASD disclosure in work settings, there is a lack of empirical research directly assessing stakeholder perceptions of such disclosure. The goal of this small sample, exploratory study was to evaluate the implementation of an explanatory disclosure strategy (i.e., the use of an ASD disclosure booklet) on the basis of gathered perceptions from the perspectives of key stakeholders: the client/employee with ASD, the supported employment staff (e.g., case managers, job coaches), and non-ASD coworkers. Research was conducted in collaboration with the supported employment services office of United Cerebral Palsy (UCP). Workers with ASD were invited to develop individualized disclosure booklets, which were shared with and evaluated by the key stakeholder groups. Results provide quantitative and qualitative descriptions of perceived benefits and risks of such disclosure. Positive feedback was gathered across three stakeholder groups with regards to the ease of developing booklets, comfort with information shared, and perceived understanding/accuracy of booklet material. Additionally, all groups were able to identify both benefits and risks of sharing booklets in the workplace with perceived benefits outweighing risks.

Explanatory Autism Disclosure in the Workplace: Perspectives of Key Stakeholder Groups

Disclosing personal information with other people often leads to the development of meaningful social relationships. Social relationships are critical to the emotional and physical well-being of all individuals, especially those with developmental disabilities (Garcia-Villamizar & Hughes, 2007). Such disclosure allows individuals not only to feel more comfortable about expressing themselves in a given environment, but also increases opportunities to interact with acquaintances, friends, and coworkers (Jourard, 1959; Thompson, 1982). Recent research suggests that there are many benefits to personal disclosure of a stigmatized condition, particularly in creating an atmosphere of acceptance in the job setting (Inge & Targett, 2008; Madaus, 2008; Munir, Leka, & Griffiths, 2005; Rocco, 2004). By disclosing their disability, some workers experience social integration in the work environment, primarily through their coworkers' deeper understanding of the individual's condition and his/her need for certain accommodations in the workplace (Chadsey, Shelden, Horn, & Cimera, 1999; Hagner, 2003; Helm & Whelley, 2000; Inge & Targett, 2008; Munir, Leka, & Griffiths, 2005; Scheid, 1999). Others unfortunately endure the risks of stigmatization as a result of their disclosure, with employers and coworkers believing that they are incompetent or unable to perform due to their disability (Allen & Carlson, 2003; Barnes, Mercer, & Shakespeare, 1999; Lawthom & Goodley, 2005).

When individuals have developmental disorders which restrict their communication abilities, social interactions are impaired, as is the case with Autism Spectrum Disorders (ASD). ASD is a neurologically-based developmental disorder characterized by mild to severe impairments in verbal and nonverbal communication, impaired social and affective behaviors, and unusual repetitive tendencies (Hagner & Cooney, 2005; Standifer, 2009). Not only do these individuals face challenges in the workplace as a result of their ASD characteristics, but also due

to the attitudes, perceptions, and misunderstandings of non-ASD employers and coworkers. Disclosure may offer a way for these individuals to connect with others in the workplace.

The workplace environment offers numerous social opportunities (Steward; 1985), but people with ASD encounter particular difficulties gaining access to and thriving in their place of employment. For most adults with ASD, unemployment and underemployment rates are high, even for high functioning individuals on the spectrum (i.e. those with intact cognitive abilities, average or above average IQ) who are qualified and capable of performing work tasks (Howlin, 2007). Even those who are employed may lack interaction experiences in the workplace (Chadsey & Beyer, 2001; Hatch, 1993). Specifically, individuals diagnosed with ASD encounter social difficulties ranging from communicating their thoughts to selecting appropriate responses in social situations (Standifer, 2009).

This study was developed based on an understanding of the employment challenges ASD workers face as a result of the characteristic social and behavioral difficulties associated with their condition. The proposed research examines one possible strategy, explanatory disclosure, for eliminating potential negative attitudes and misunderstandings related to the nature of ASD. For the purposes of this study, disclosure is defined as the communication of information to another about the nature of one's disability (Thompson, 1982). Specifically, explanatory ASD disclosure refers to sharing information that explains the disability in ways which would promote the understanding of ASD and provides strategies for enhanced cooperation of ASD and non-ASD individuals in the work environment (Job Accommodation Network, 2009; Mawhood & Howlin, 1999). A recent review of the autobiographical literature from adults with ASD cited both the benefits and risks associated with the disclosure of ASD in the workplace (Brownlow, 2010). However, no empirical research was located which assessed the perceptions of non-ASD individuals, such as coworkers, toward such disclosure.

Given this gap in the research literature, empirical research is needed to determine whether a particular strategy of explanatory disclosure, such as the use of an informational booklet, will gain favorable responses from *all* key stakeholders: the employee with ASD, the supported employment staff assisting the ASD worker (e.g., job coaches and case managers), and non-ASD coworkers. The study was designed to assess whether perceptions gathered from different stakeholders would highlight more benefits than risks in the use of such disclosure in the workplace.

Considering the puzzling nature of ASD, it is important to address how individuals with ASD behave in the workplace as well as strategies for improving employment. The following literature review is organized into two sections: (1) Issues with ASD in the workplace, including supported employment, and (2) Rationale and recommendations for disability disclosure.

Issues with ASD in the Workplace

With the introduction of the Americans with Disabilities Act (2010), legislation offered disabled individuals the fair opportunity to seek employment provided that they could perform the essential tasks of the job. These basic employment rights work to prevent discrimination and harassment against all workers with disabilities including those with ASD. In Scheid's (1999) national survey of 190 companies, he found that organizations taking active steps to comply with the ADA reported a more positive and supportive work environment for *all* workers. Many studies acknowledge the association between a positive workplace environment and greater coworker/supervisor acceptance for individuals with disabilities (Butterworth, Hagner, Helm, & Whelley, 2000; Hagner, 2003; Scheid, 1999; Stone & Colella, 1996).

Regardless of legislation, in a competitive labor market, a person with an observable, undesirable injury, illness, or disability is at a significant disadvantage; anything that makes an individual perceivably different serves as a roadblock to the development of social relationships both inside and outside of the work force (Allen & Carlson, 2003; Comer & Piliavin, 1972;

Gray, 1993; Peyton, 2004; Standifer, 2009; Stone & Colella, 1996; Torrey, 1997; Wahl, 1992).

People with ASD may be at risk due to the breadth and nature of their impaired social and communication skills, unusual behaviors, and repetitive and sensory issues (Standifer, 2009).

Because these factors serve as obstacles which can distance ASD individuals in the work environment and contribute to coworkers' misunderstandings about characteristic behaviors, they are explained in greater detail below. Additionally, supported employment, one general approach to improve employment opportunities for those with ASD, is further described.

Impaired social and communication skills. Communication allows people to interpret others' basic needs and functions: thoughts, feelings, and desires (Pronin, Fleming, & Steffel, 2008). In the work place, communication takes on a more specific purpose by enabling employees and employers to efficaciously coexist and work together in a productive manner. Impairments in verbal and nonverbal communication as well as improper social behaviors can be considered potential obstacles to a positive work environment (Hagner & Cooney, 2003). While simple conversations are considered to be second nature for most people, ASD individuals often experience difficulty understanding implications or context in speech, expressing their thoughts and emotions, and discerning different tones of voice, facial expressions, or gestures (Hurlbutt & Chalmers, 2002; Olney, 2000). As a result, social relationships may be strained, and coworkers may experience difficulties comprehending the ASD individual's thoughts and feelings regarding work tasks.

People with ASD often show unique patterns of social interests, social understanding and ways of interacting. Many coworkers and employers find it challenging to approach some ASD individuals who appear uninterested in social interaction and friendships (Koning & Magill-Evans, 2001; Tantam, 1991). For instance, some individuals with ASD have difficulty expressing behaviors that encourage interaction, such as maintaining eye contact or showing facial expressions appropriate to the topic of conversation (Standifer, 2009). Others with ASD are very

outgoing, yet may have trouble interpreting social cues, such as humor, sarcasm, and figures of speech (Bourgondien, 1997; Camarena & Sarigiani, 2009). Those who are social may fixate on a favorite topic or activity which is likely to be over expressed in conversation (Hurlbutt & Chalmers, 2004). This may not only be disruptive, but also does not allow others to connect with the conversation. Coworkers or supervisors may find it difficult to relate to an ASD individual, especially one who limits the social relationship to his or her special interests.

Most people with ASD find it difficult to pick up on unstated social expectations in the workplace—in part because they cannot always tell what others are saying with their faces, jokes or body language. People with ASD may misinterpret emotions or behaviors expressed by individuals, and often struggle to convey their own feelings as well (Bourgondien, 1997; Camarena & Sarigiani, 2009; Hurlbutt & Chalmers, 2002). Misinterpretations may arise as a result of some social behaviors that cause coworkers to feel that the ASD individual does not care about his or her feelings or topic of conversation.

Atypical and disruptive behaviors. Stone and Colella (1996) hypothesized that disruptive or unattractive characteristics of a disability tend to elicit negative reactions from workplace colleagues. In classroom settings, autistic children are often rejected by peers and teachers who treat their disruptive behaviors as signs of defiance and disrespect rather than attributes of a disability (Swaim & Morgan, 2001). The disruptive nature of autistic children's antisocial behavior is coupled with their normal physical appearance, which may lead to unfair expectations of social decorum (Gray, 1993). These children are commonly humiliated and neglected by both teachers and students who perceive their behavior as inappropriate (Gray, 1993; Peyton, 2004). In the work setting, Braddock and Bachelder (1994) found that many employers assign those individuals exhibiting atypical behaviors unfavorable jobs that lack customer interaction, and limit their inclusion in workgroup activities and promotions.

Some individuals with ASD may engage in particularly interfering behaviors that are often misinterpreted and not tolerated in the workplace (Smith, 1990). For instance, people with ASD may be hyper-stimulated by a variety of different sensations, which often cause disruptive reactions (Burt, Fuller, & Lewis, 1991). A monotonous car alarm at work may be bothersome for everyone, but could be particularly vexing for an ASD individual with hypersensitivity to sounds. He or she may overreact to this sensation by holding his or her ears tightly, or humming while pacing in order to tune out the noise. Such reactions to altered perceptions of sensitivity tend to distance ASD individuals from others in the workplace because they are seen as disruptive or atypical (Hendricks, 2010).

Further, some people with ASD find ways to calm themselves through ritualistic means, such as rhythmic movements, walking, humming, hand flapping, or counting (Standifer, 2009). Without a structured work schedule or tasks, some people with ASD may have greater trouble setting priorities, making practical judgments, or dealing with unexpected situations that arise in the workplace. In these situations, people with ASD may feel overwhelmed and likely turn to these calming rituals (Lingsom, 2008; Simpson, 2004). In turn, non-ASD individuals in the workplace may find these tendencies disruptive, limiting the development of functional relationships at work. Despite such challenges, there are several ways to improve employment opportunities for those with ASD. One general strategy is through supported employment services.

Supported employment. For individuals with disabilities who need additional help at the job site, supported employment services can help provide a stable and predictable work environment where the disabled person can become an independent, contributing member of the workforce (Garcia-Villamisar & Hughes, 2007). These services allow many individuals with cognitive disabilities, such as ASD, the opportunity to keep up in the competitive labor market (Cimera, 2007). For example, supported employees with ASD are typically paired with a job

coach who accompanies the employee to the job and assists him or her in the learning of necessary work tasks and other training matters (Hagner & Cooney, 2003). Supported services may also promote successful employment experiences for individuals with ASD by including enhancement of interactions between ASD and non-ASD individuals. Because many supervisors and business managers have little formal training in managing disabled individuals, the job coach acts as an intermediary to ensure appropriate collaboration (Gates & Kantrowitz, 1996). The overwhelming success of supported employment programs has been widely documented for people with cognitive disabilities generally (Cimera, 2008; Cramm, Tebra, & Finkenflugel, 2008; Garcia-Villamizar & Hughes, 2007; Job Accommodation Network, 2009; Hagner, 2003; Ruef & Turnbull, 2002; Rusch & Braddock, 2004; Unger & Kregel, 2003) and particularly those with ASD (Campbell et al., 2007; Hagner & Cooney, 2005; Hiller et al., 2007). The success of supported employment services both for the individual with ASD and the work site is well-documented, yet recent studies acknowledge several challenges to delivering successful employment services, specifically due to the lack of preparation and training of job coaches (Conley, 2003; Flynn, Wacker, Berg, Green, & Hurd, 1991; West, Revell, & Wehman, 1998).

Many supported employment specialists hired by supported employment services assume the responsibilities of a job coach with very little knowledge about ASD and how it affects the individual (Allen & Tynan, 2000). The lack of personnel preparation in autism is perhaps the largest contributor to shaping job coaches' attitudes towards working with ASD individuals (Allen & Tynan, 2000; Baker & Bissmire, 2000; Chadsey & Beyer, 2001; Conley, 2003; Flynn, Wacker, Berg, Green, & Hurd, 1991; Scheuermann, Webber, Boutot, & Goodwin, 2003). The training a job coach receives has the potential to influence his or her capability to feel comfortable and efficacious performing necessary duties. Without specific direction guiding the job coach, he or she may feel inadequate and uneasy when trying to assist the person with ASD (Allen & Tynan, 2000; Baker & Bissmire, 2000; McDonnell, 1997; Moon, Goodall, Barcus, &

Brooke, 1986). Additionally, the high turn-over rate and part-time status of many job coaches does not allow sufficient time for adequate training, which contributes to feeling uncomfortable working with the ASD individual (Flynn, Wacker, Berg, Green, & Hurd, 1991).

Previous studies have evaluated the effect of staff training courses to increase job coaches' knowledge of effective management and response to challenging behaviors with individuals who have mental retardation or physical disabilities. These studies overwhelmingly indicate that staff attitudes, confidence, and self-efficacy improved after being exposed to training classes regarding common issues necessary to helping those with disabilities (Allen & Tynan, 2000; Conley, 2003; Baker & Bissmire, 2000; McDonnell, 1997; McDonnell et al., 1999; O'Neill, Williams, Sprague, Horner, & Albin, 1993; Scheuermann, Webber, Boutot, & Goodwin, 2003; Scott, 1996). However, no existing studies were located testing such training methods for those who work with ASD individuals (Wehman & Parent, 1996). Furthermore, the existing studies only offer general guidelines for working with disabled people, not focusing specifically on the diverse and unique needs of the ASD individual assigned to the particular job coach (McDonnell et al., 1999).

Summary and implications. Among other benefits, employment offers individuals with ASD greater autonomy and the opportunity to form social relationships (Garcia-Villamizar, Ross, & Wehman, 2000; Garcia-Villamizar & Hughes, 2007; Jahoda, Kemp, Riddell, Banks, 2007; Persson, 2000). However, many ASD individuals face challenges in the work environment due to the social and behavioral characteristics of their disability as well as others' misunderstandings. Further, while supported employment services offer ASD individuals the opportunity to become successful employees in competitive workplaces, they are not without their limitations.

Knowledge of ASD is a key component to eliminating many misunderstandings. Simpson (2001) states, "The countless permutations and combinations of social interactions, language,

learning, sensory, and behavior deficits and excesses found in these individuals, in combinations with their wide range of abilities, developmental levels, isolated skills, and unique personalities makes autism an especially *baffling* disability” (pg. 69). Thus, education about ASD should help overcome misunderstandings and “bafflement.” The current study explores the use of explanatory disclosure information regarding the ASD individual’s impaired social and communication skills, unusual behaviors, and repetitive and sensory issues as an informative strategy for educating those that work with individuals with ASD. The following section presents the rationale and research on disability disclosure to provide a broader context for the specific explanatory disclosure strategy.

Rationale and Recommendations for Disability Disclosure

Self-disclosure has been identified as an important area to be considered in helping people develop their relationships at work (Job Accommodation Network, 2009). While self-disclosure is a complex decision for any individual, those who are diagnosed with ASD may find it particularly difficult to a) weigh the benefits/risks of disclosing in the workplace, and b) find a suitable method of disclosure. Although there is literature that provides recommendations for individuals with disabilities to consider when making the decision to disclose (Bishop & Allen, 2001; Marrone, Gandolfo, Gold, & Hoff, 1998), the decision to do so is exceedingly difficult, especially in a work setting where one may be unfamiliar and uncomfortable with certain coworkers or supervisors.

Employer and coworker attitudes are mixed with regard to disability disclosure, with some responding favorably to individuals who disclose (Christman & Slaten, 1991; Singletary & Hebl, 2009) and others citing that disclosure produces discrimination in hiring, advancement, treatment, and evaluations (Fesko, 2001; Goldberg, Killen, & O’Day, 2005; Guskin, 1982). The existing literature is limited in that it generally focuses on disclosing physical or psychological impairments (Allen & Carlson, 2003; Belgrave & Mills, 1981; Christman & Slaten, 1991; Comer

& Piliavin, 1972; Inge & Targett, 2008; Kolodziej & Johnson, 1996) rather than specific developmental disabilities, such as ASD. The following sections describe the three main stakeholder roles (ASD individual, job coach, and coworker) with regards to the disclosure process.

Disabled individuals' perceptions and rationale for disclosing. Disclosure is a goal-directed behavior, and individuals may have a variety of goals for disclosing their disability in the workplace (Derlega & Grzelak, 1979). Ohtake and Chadsey (1999) found that by simply disclosing personal information, such as interests, likes, and dislikes, people with disabilities were able to facilitate conversation and friendships with coworkers. Others chose to disclose in order to express thoughts and feelings so that they could build intimacy within personal relationships (Chaudoir & Fisher, 2010). Explanatory disability disclosure can reduce the amount of anxiety individuals with disabilities feel interacting at work by providing a mechanism for education and understanding of the disability (Davis, 1961; Richeson & Shelton, 2007). Finally, for some disabled individuals, disclosure may be an attempt to reduce demands in the workplace, or ask for possible accommodations (Lingsom, 2008). Accommodations may greatly enhance the ASD individual's working abilities and are generally provided in five areas: training programs, work assignments, job duties, schedules, and work area (Unger & Kregel, 2003).

Some ASD individuals may choose not to disclose. The concealment of a disability may be prompted by the anticipation of negative and stereotypical attitudes (Allen & Carlson, 2003). Several concurrent themes were identified in Allen and Carlson's (2003) evaluation of reasons to conceal a cognitive or learning disability: to preserve self-esteem, to avoid emotionally hurtful responses from others, to circumvent negative employer attitudes regarding productivity, and it was seen as a cultural norm not to complain about a disability. More specifically, Davidson and Henderson (2010) found that individuals with ASD who choose not to disclose attempt to guard

themselves against the societal stigma, believing that some people will not be able to understand the diagnosis, or will perceive them as less capable.

While there are certainly risks and benefits involved in disclosure, several recommendations have been proposed for disclosing a disability in the workplace. Specifically, an individual should disclose to employers when accommodations are needed in the workplace (Inge & Targett, 2008). Many employers appear willing to grant accommodations that are straightforward, inexpensive, and easy to make (Granger, Baron, & Robinson, 1997; Harlan & Robert, 1998). The Job Accommodation Network (1999) suggests that the method of disclosure should avoid a focus on labels or clinical descriptions, and instead, focus on how the person's disability can or will affect his or her tasks or interactions in the work environment. The explanatory disclosure booklets evaluated in this study follow this recommendation, offering the coworker information related to how the ASD individual can perform and succeed in job functions with the help of coworkers, job coaches, and accommodations (e.g. fixed schedule, same shift and work tasks, attention to particular social differences and behaviors).

Job coach perceptions and rationale. Due to the number of job coaches who lack specific ASD training (Allen & Tynan, 2000; Baker & Bissmire, 2000; McDonnell, 1997; Moon, Goodall, Barcus, & Brooke, 1986), explanatory disclosure may offer these workers the opportunity to receive guided instruction in handling more issues for a specific person whom they are assisting in the workplace. Since ASD symptoms vary from person to person (Simpson, 2001), individualized explanatory disclosure benefits the job coaches in that they are better prepared to assist the individual in the workplace. Competent and capable job coaches are not only necessary for the ASD individual, but also for the coworkers and employers in the work place. Many non-ASD employees found that the availability of job coaches was generally helpful to the organization as a whole, as they did not have the time or abilities to properly teach the supported employee certain tasks at work (Cramm, Tebra, & Finkenflugel, 2008).

Job coaches also have the responsibility of providing guidance for social interaction between ASD and non-ASD individuals in the workplace. Most employers and coworkers found that a trained and knowledgeable job coach was an effective mediator if an issue arose with the behavior of the ASD individual (Unger & Kregel, 2003). Explanatory disclosure may have the potential to increase job coach understanding regarding the individual's needs as well as to increase their skill set for working with the individual and his or her employers.

Coworker perceptions and rationale. Nondisabled coworkers may experience uncertainty and a lack of understanding regarding the nature of the person's disability; this may lead to feelings of discomfort in disabled-nondisabled interactions (Thompson, 1982). The uncertain individual does not have the necessary education or information about how the disability affects the other person, and as a result, may formulate his or her own inappropriate expectations regarding the disabled person's abilities (Bolman, 2008; Muller, Schuler, Burton, & Yates, 2003). A lack of experience or education may impair the coworker's ability to establish meaningful relationships with one another (Butterworth & Pitt-Catsouphes, 1997; Pronin, Fleming, & Steffel, 2008). Specifically, coworkers expressed concerns about not having the resources, such as time, experience, or knowledge about the disability, in order to develop meaningful relationships (Buttersworth & Pitt-Catsouphes, 1997).

The explanatory disclosure method embraces the idea of educating coworkers in the work environment so that they are able to interact more confidently and appropriately with those who are disabled (Chadsey & Beyer, 2001; Petty & Fussell, 1997; Rusch & Hughes, 1989; Unger, Parent, Gibson, & Kane-Johnson, 1998). Explanatory disclosure communicates information to the coworker about the nature of the ASD individual's disability (i.e. certain behaviors and issues to expect in the workplace, the dynamic range of cognitions, behaviors, and social/communication difficulties). There is an exigence to assess the potential impact of a

specific explanatory disclosure strategy for this group due to their close working relationships with the ASD individual.

Current Study

This pilot study focuses on evaluating an explanatory disclosure strategy based on the perceptions of three key stakeholders: the client/individual with ASD, his or her supported employment staff, and non-ASD coworkers. Despite the frequent recommendations for the use of explanatory disclosure of ASD in the work environment, no existing research was located that examines the perceptions of the proposed disclosure strategy.

The research was conducted with the collaboration of a supported employment services agency, United Cerebral Palsy (UCP). Individuals with ASD receiving supported employment services from UCP were invited to develop explanatory booklets and share them with their parents, job coaches, and coworkers. Booklets included information the ASD client wanted to share with his or her non-ASD coworkers: informative description of the disability, how the individual's behaviors affect his or her work tasks and interactions, and recommendations for working together. Reactions about the booklet-making and sharing processes were collected by the research team from any stakeholders who chose to share their perceptions in questionnaire format. It was important to assess the three stakeholders' reactions for several reasons. Specifically for the client, we wanted to measure whether this method of disclosure would be a viable strategy to use in the workplace and with other individuals. The booklets were designed to function as ASD training tools both for the coworkers/supervisors as well as job coaches who may not have received adequate training to work closely with the ASD individual. Considering the important role of supported employment staff as key people in helping the individual decide if and how to disclose the disability in the work setting, they are well poised to give feedback about potential risks and benefits of the booklet. Similarly, coworkers and supervisors are people

who work closely with the ASD individual, and assessing their reactions to the booklet use was important for the successful development of strong working relationships.

To minimize intrusion of the research project into the working relationships of UCP clients with their UCP staff, all service aspects of the project were under the supervision of UCP staff (i.e., the development and sharing of individualized explanatory disclosure booklets, making the decisions about whether and how to use the booklet for disclosure purposes). In contrast, the data collection aspects of the project were the primary focus of the researchers (i.e., gathering reactions and perceptions about the booklet-making and sharing process in the form of questionnaires from the aforementioned stakeholders). The study assessed whether the booklet was a viable disclosure model by exploring perceptions of engagement in process, cognitive reactions, affective reactions, and perceived benefits and risks of sharing in the workplace.

Methods

Participants

The larger, ongoing study of which the current project is a part will involve collection of data on four groups of participants: UCP clients, UCP staff, parents/guardians, and coworkers. The focus of this early pilot study is on information gathered from ASD clients, UCP staff, and parents.

ASD client. Data were collected regarding the experience of six (6) adults receiving supported employment services from the UCP organization in Bloomington, Illinois. Clients were invited to participate in the research study only if they were (a) over the age of 18, (b) receiving supported employment services from UCP for an ASD or a related cognitive, social, or intellectual disability, (c) developing/using explanatory written materials with the UCP, and (d) had sufficient verbal and intellectual ability to engage in the booklet making-process and questionnaire responses either independently or with UCP staff assistance (see Table 1).

Clients ranged in age from 21-34 ($M=25.17$, $SD=4.62$). Responses were collected from four males and two females. Four individuals were on the Autism Spectrum and two were

identified as having mild to moderate mental impairments. One individual was unemployed and five were employed, with all working in service sector jobs, such as dining assistance and custodial services. Five worked part-time (9-15 hours a week), and of those employed, three had been working for over 12 months in length.

Supported employment staff. Additionally, responses were gathered from the UCP supported employment specialists (e.g., UCP supervisor, job coaches). Job coaches were chosen by the UCP clients as individuals with whom they wanted to share their booklets. The five female respondents ranged in age from 29-45 and had varying levels of experience working with ASD. Three were UCP case managers, one was a job coach, and one was the receptionist.

Parents/guardians. Feedback was also collected from two parents. Both were mothers of the UCP clients. No additional demographic information was collected on parents.

Procedures and Measures

Data were collected in the context of services provided at the offices and worksites associated with the UCP employment program. To minimize the intrusion of the research project into the working relationships of UCP clients and staff, UCP staff members were trained by the researchers to collect informed consent and administer questionnaires to clients and coworkers. There was a division of responsibilities with the UCP staff and clients making all formal decisions about intervention procedures (e.g., booklet material and use), and the research team taking responsibility for the research procedures (e.g., developing questionnaires designed to assess the reactions to such booklet disclosure).

Intervention procedures. Individualized explanatory disability disclosure booklets were developed by UCP staff and clients working together. The research team provided UCP staff with two possible booklet templates, ASD specific and general. Templates were designed to describe the disability in a general manner, and individuals were free to include any information relevant to describing their disability, particularly in the work environment. Such information

included personal interests, expected behaviors at work, and helpful suggestions for understanding the individual (see Appendix for sample template material). After making the booklet, UCP staff engaged clients in a discussion of whether and how the booklet would be shared with others. All decisions regarding such sharing of the disclosure booklet were made by UCP clients. Initial sharing decisions were made first with individuals relatively close to the client, including their parents/guardians and job coaches. With the assistance and support of employment staff, the UCP client decided when, how, and with whom to share the booklet material. Similar procedures will be used to share with coworkers and supervisors at the job site.

Research procedures. The research procedures involved participant completion of questionnaires assessing reactions to the use of the disclosure booklet. The research procedures called for collection of data in four phases. UCP staff were trained to assist the researchers by collecting informed consent from the appropriate stakeholders with whom the booklet was shared. All research information was handled securely by the UCP receptionist who was in charge of maintaining a coding system so that client names were not displayed on forms in order to protect respondent confidentiality and to increase the likelihood of authentic responses. All forms were placed in a secured box at the UCP employment services site. Completed questionnaires were picked up on a weekly basis from the secured box at the UCP employment services site.

Phase I: Booklet development. Following each booklet-making session, the client and UCP staff member responsible for helping the client make the booklet completed the Phase I: Client and Phase I: Staff Questionnaires, respectively, to evaluate the booklet-making process (see Appendix for questionnaires).

Phase II: Initial sharing. Clients who expressed interest in sharing their booklets with their parents/guardians and job coaches did so at the UCP site. After reading the booklet, job coaches were asked to fill out the Job Coach Questionnaire. Additionally, parents/guardians

formally invited to read the booklet by UCP clients filled out a Parent/Guardian Response Questionnaire (see Appendix for questionnaires).

Research measures. All questionnaires were developed by the research team specifically for this study. To increase participation, questions were formatted in order to ensure that items evaluated the booklet-making, sharing, and reading processes, and *not* the client. While none of these questionnaires had been previously used or evaluated, the items were straightforward in assessing the evaluations and perceptions of the disclosure booklet used in this exploratory study. Specifically, questionnaires assessed reactions with respect to the following five categories: (1) Engagement in process (i.e., ease of booklet development), (2) Affective response (i.e., general liking of booklet, comfort), (3) Cognitive response (i.e., perceived understanding and accuracy), (4) Perceived benefits and risks, and (5) Perceptions of impact on working relationships. At this time, data have not been collected to assess the perceptions of impact on working relationships. All questionnaires featured a mixed structure of open-ended questions and Likert scale items.

Phase I measures: Booklet development. UCP clients completed a 12-item Client Questionnaire that included two types of items, open-ended responses and structured 3-point scale items questions. A 3-point scale was implemented to simplify the language for clients, evaluating such structured items, like the process of making the booklet (e.g., ease), their understanding of the booklet, and the booklet itself (e.g., how well it describes them, what they like about it, perceptions of helpfulness). Clients were also asked to indicate with whom they would like to share the booklet. A parallel 11-item Staff Questionnaire was completed by UCP staff assisting clients in the development of the booklet. Items were similar to those included in the Client Questionnaire just described (e.g., ease of making the booklet, perceptions of helpfulness), except following a 5-point format. In addition, staff members completed four specific items on a 1-5 Likert scale indicating whether they believed sharing the booklet with job coaches and/or coworkers would be beneficial, appropriate, risky, and useful. Responses to these

items were combined into a single scale, referred to as the Benefits Scale in the results section. This scale was an overall measure of perceived benefits and risks, with higher scores indicating greater perception of benefits. The mean of four aforementioned items was calculated twice, once for perceived benefits and risks of sharing with a job coach, and another for sharing with a coworker. The resulting two sets of 4-items were completed as two distinct but parallel scale scores. Additionally, staff filled out a brief demographic informational form (Client Background Information Form) describing their client's age, gender, job placement, and disability condition.

Phase II: Initial sharing. Job coaches completed a 14-item Job Coach Questionnaire after reading a client's booklet. Respondents were asked to share a variety of impressions about the booklet (e.g., perceived ease of reading the information, possible benefits/risks) in both structured and open-ended items. In addition, they responded to sets of items that asked about the appropriateness of using the booklet at a job site, its impact on their self-efficacy and confidence, and perceived effects on job coach-client relationship. Finally, they were asked to provide some basic demographic information. The Parent/Guardian Questionnaire contained items parallel to those in the Job Coach Questionnaire. Questions focused on the perceived ease/comfort of reading the information as well as identifying benefits/risks of having their sons or daughters share the booklets in the workplace and with job coaches. Parents also completed the Benefits Scale.

Research Design and Data Analysis

This quasi-experimental research was conducted as a small-scale pilot study. Both quantitative and qualitative data were collected to allow analysis of perceived benefits and risks of developing, reading, and sharing the explanatory disclosure booklet. However, the collected data were incomplete (see Table 2). For the six UCP clients and six staff members who developed booklets, only three clients and five staff members completed corresponding questionnaires. Additionally, the booklets were shared with two parents, one job coach, and one

UCP receptionist. Given the small sample size and non-experimental nature of the study, emphasis in the following results section is placed on descriptive statistics. In addition, some items were dropped. Most notably, the categorical analysis of perceptions of impact on working relationships was not conducted due to the unavailability of sufficient coworker and job coach data. With the exception of the aforementioned Benefits Scale, all analyses were conducted at the item level. Results were analyzed and reported in one of five separate categories: (1) Engagement in process, (2) Affective response, (3) Cognitive response, (4) Perceptions of general benefits and risks, (5) Perceptions of impact on working relationships.

Results

Engagement in Process

The mechanisms of the engagement process were assessed in terms of the length of time to develop booklets, the ease of development, and clients' willingness to share.

Length of time and use of template. UCP staff that helped clients develop booklets reported that it took 1-3 hours for each ($M=1.70$, $SD=.84$). UCP staff members all elected to use one of the two templates, and unanimously cited that they used the template "a great deal," the highest degree on the scale. Additionally, four out of five UCP staff members reported using the ASD template over the more generic disability template for the development of clients' booklets.

Ease of process. UCP staff and clients were asked to express how easy the booklet was to complete. The scales used differed in complexity (5-point scale for staff; 3-point hard/average/easy scale for clients). To facilitate comparison across groups, the 1-5 Likert scale for the staff was condensed to match the client scale so that respondents indicating that they strongly agreed the booklet was easy to develop would fall into the "easy" category (<3 /hard, 3 /midpoint, >3 /easy). The results, presented in the top portion of Table 3, revealed that all respondents unanimously agreed that the booklet developing process was easy.

Willingness to share. Out of three client respondents, all three expressed interest in sharing with a job coach and coworker (see bottom of Table 3). As seen, there are varying degrees of enthusiasm/preference. However, all responses ranged in the two highest subsets of the scale, “I would like to share” and “I would love to share.” Additionally, respondents were able to identify other individuals from a provided list with whom they would feel comfortable sharing their booklet. Clients chose individuals with whom they had already developed close relationships (friends, family members) as opposed to sharing their booklet with customers, teachers, and strangers.

Cognitive Reactions

The underlying cognitive factors assessed in the booklet process included respondents’ perceptions of the booklet’s ability to accurately describe the client as well as the client’s understanding of booklet material.

Perceived accuracy in describing client. All respondents were asked how well the booklet described the client. Once again, 5-point response scales (for parents and UCP staff) were condensed to facilitate comparisons with the UCP client response (on a 3-point scale). Respondents across all groups unanimously agreed that the booklet was strongly accurate in describing the client. Results are shown in the top portion of Table 4.

Client’s understanding of booklet. Respondents were asked whether they believed the client understood booklet material. Once again, results were unanimous across respondents, indicating that they perceived the client understood the information in the booklet (bottom; Table 4).

Affective Reactions

Client liking. Clients were asked to indicate how much they liked their booklet material (yes/sort of/no), and three of three responded “yes.” In response to an open-ended question asking what they liked most about their booklets, all three responses highlighted the potential of

the booklet in enhancing understanding of ASD and work relationships (i.e., It will help others communicate better with me, it will help others understand autism, it could help expedite the process of finding someone to hire me).

Comfort levels. UCP staff members and parents/guardians shared their comfort levels in receiving the booklet material on a 1-5 scale where “5” implied that they felt very comfortable reading the booklet. On average, UCP staff members strongly agreed that they felt comfortable engaging the client in the booklet development process ($M=4.6$, $SD=.89$, $N=5$). Additionally, parents/guardians felt strongly comfortable reading the booklet ($M=5.0$, $SD=.00$, $N=2$).

Perceived Benefits and Risks

Benefits scale. UCP staff and parents were asked whether they felt it would be helpful to share booklets with job coaches and coworkers. As mentioned earlier, this scale was an overall measure of perceived benefits and risks, with higher scores indicating greater perceptions of benefits and lower scores indicating greater perceptions of risks. It was found that both groups perceived sharing with both job coaches and coworkers to be highly beneficial as demonstrated in Table 5 (note that all $M > 4.50$).

Qualitative responses. In response to open-ended prompts, both clients and their parents were asked to identify perceived benefits and risks of sharing their booklet in the workplace. Responses are recorded verbatim in Table 6. Clients identified benefits that highlighted the potential of the booklet to promote a better understanding of ASD in the work environment and improve working relationships (e.g., It will help others understand autism). Only one of three individuals noted a possible risk in “dealing with bigots.” Parents highlighted the booklet’s potential to help garner a better understanding of social differences and unique qualities. Parent respondents perceived a risk in being labeled as disabled (e.g., Coworkers will be hurtful), and questioned whether others would actually take the time to read the booklet material.

Discussion

Many individuals with ASD are unemployed, underemployed, or face several challenges in the workplace due to their social and communication differences (Peyton, 2004; Standifer, 2009). While several general strategies for improving employment for those with ASD have been recommended, no empirical research was located studying the effects of disclosing ASD in the work environment as a means of ameliorating work opportunities. This study was conducted in the context of supported employment services, which have had widely documented success in assisting individuals with cognitive disabilities, such as ASD (Cimera, 2008; Garcia-Villamizar & Hughes, 2007; Hagner, 2003; Job Accommodation Network, 2009). The small-scale, pilot study focused on evaluating a specific booklet disclosure strategy by assessing the reactions of three key stakeholders in the overall development and sharing processes. Perceived benefits of using such disclosure were thought to outweigh perceived risks in all respondents. Overall, we received positive feedback across UCP clients, staff, and parents in all four assessed categories (engagement in process, affective reactions, cognitive reactions, perceived benefits and risks), suggesting that booklet disclosure may be a viable strategy for improving employment.

Engagement in Process

Engagement in the process involved assessment of ease and the degree to which supported employment clients and their staff actively engaged in the booklet making process. Individuals who were engaged in the booklet making process—by which we mean completed the booklet, used the template, and found the process relatively easy—were likely to conceive that the booklet was a viable strategy for promoting employment success.

There were several indications of active engagement. First, six (6) individuals were invited by staff to develop disclosure booklets, and all six agreed. The loss of three (3) clients' data was due to the reluctance to complete the research questionnaire rather than disinterest in making or sharing the booklet. This initial interest in developing disclosure material was important because it suggests that individuals with ASD felt comfortable with the project.

Second, UCP staff and clients were interested in continuing with this ongoing project, suggesting that they were willing to invest in this particular disclosure strategy. All clients who responded expressed interest in sharing with a job coach and coworker. Additionally, clients were able to identify individuals with whom they would like to share their booklet. Allen and Carlson (2003) identified the recipient of disclosure information as an important factor to consider when choosing to disclose or conceal a disability. These results showed that clients may be considering the risks associated with disclosing a disability as none chose to share with strangers or customers at work. Instead, they opted to share with close friends and family members, people who they already feel comfortable with and have had lengthy relationships.

Third, given the understaffing and lean budget of most supported employment agencies, it was especially important to find that UCP staff were willing to invest time and effort in developing individualized disclosure booklets with their clients. UCP clients and staff ranged in the length of time it took to develop the booklets, from one to three hours. This suggests that the development process was not particularly strenuous, although certain clients required lengthier times to develop their material. Despite the length of development, both individuals with ASD and their supported employment staff agreed that the development process was easy. Feedback from these stakeholders was critical to determine whether the development process was relatively easy, could be completed in an efficient, timely manner, and thus worthy in investing time and effort.

Additionally, all staff indicated that they used the provided templates extensively. The ASD specific template (used by five of six), appears to have been preferred by UCP clients and staff when creating their own personalized disclosure material. Template information was designed to provide many examples of how ASD affects the individual in the workplace. Individuals with ASD may have found the examples relevant to them and chose to integrate even more personal information. Their ability to assess the examples in the template, analyze ways in

which these examples pertained to them, and include their own specific criteria were indicators that they were engaged in the development process.

Affective Reactions

Perhaps most important to evaluating this disclosure strategy was assessing affective reactions. The ASD individuals' feedback is particularly important to consider due to the possibility of other strategies of disclosure to cause anxiety and unease (Davis, 1961; Richeson & Shelton, 2007). Explanatory booklet disclosure, as opposed to verbal disclosure, may reduce the amount of anxiety and pressure individuals feel when attempting to disclose their ASD in a way that enhances understanding. The initial commitment to use this strategy was strong as all responding individuals with ASD expressed liking their booklets and showed interest in sharing them with others. They were able to give specific reasoning as to why they believed this booklet would be beneficial to share with others. Specifically, clients focused on the booklet's potential as a gateway for understanding ASD as well as improving working relationships. Additionally, everybody who read the booklets was comfortable with the information presented.

Cognitive Reactions

Cognitive reactions involved the assessment of booklet accuracy in describing the individual with ASD as well as his or her understanding of the booklet. All respondents unanimously agreed that the booklet accurately described the client. Also, evidence gathered from all stakeholders (clients, parents, staff) suggests that participants in the study were able to understand the booklet material. This is particularly important to note for several reasons. First, a client's understanding of his or her own booklet information is integral. If individuals with ASD understand the material, they are better able to explain their disability to others and answer questions. Secondly, for individuals with high-functioning ASD, the booklet may promote self-understanding. Specifically, they may realize how their disability affects their work performance and behavior in the workplace in ways they may not have previously considered. In doing so, the

booklet may provide the necessary empowerment for the individual to recognize what he or she needs in order to be a successful employee. Finally, since disclosure is a goal-oriented process, individuals may realize that disclosing ASD may allow them access to possible accommodations (Lingsom, 2008).

Perceived Benefits and Risks

While self-disclosure is a complex decision for any individual, those with ASD may find it particularly difficult to a) weigh the benefits/risks of disclosing in the workplace, and b) find a suitable method of disclosure. Although there is literature that provides recommendations for individuals with disabilities to consider when making the decision to disclose (Bishop & Allen, 2001; Marrone, Gandolfo, Gold, & Hoff, 1998), the decision to do so is exceedingly difficult. Both individuals with ASD and their parents were able to successfully identify perceived risks and benefits of sharing this disclosure material in the workplace.

Since disclosure is a goal-directed behavior, individuals may have a variety of goals for disclosing their disability in the workplace (Derlega & Grzelak, 1979). Such goals include reducing demands in the workplace, building better working relationships, and promoting an understanding of the disability (Chaudoir & Fisher, 2010; Richeson & Shelton, 2007; Unger & Kregel, 2003). It was important to assess the ASD stakeholder perceptions to find whether these stakeholders goals were the same for disclosing a disability. Perceived benefits of booklet disclosure focused on three particular themes: Greater understanding of ASD, improvement in working relationships, and recognition of the individual's desire to work as well as his or her unique abilities. By disclosing ASD, parents and clients believed that it would help others work alongside an ASD coworker and level the playing field in the workplace. Thus, the benefits that both parents and individuals with ASD perceived were similar to disclosure goals identified for other disabilities.

Concealment of a disability may be prompted by anticipation of negative and stereotypical attitudes (Allen & Carlson, 2003). Individuals with ASD and their parents were able to identify perceived risks, such as being labeled as disabled. This was important to recognize considering that ASD is a misunderstood and not readily apparent disability. It was necessary to assess that stakeholders understood and were able to identify risks of disclosure. If they perceived the risks to be greater than the benefits, they would not choose to use this particular method of disclosure.

Strengths, Limitations, and Future Direction

Assessment of the booklet's effects on client success and employment need to be taken into consideration as a part of utilizing this disclosure strategy as a regular ongoing service in supported employment agencies. One of this study's greatest strengths was that it was conducted in a naturalistic setting with ASD individuals who were already receiving supported employment services from UCP. The real life application of this study both in supported employment agencies and in the workforce was perhaps its biggest strength. Previous writings on supported employment for individuals with ASD have provided recommendations for disclosure. However, no empirical research was found directly assessing disclosure strategies in vivo, and this study serves to fill the gap in the literature. Gauging supported employment specialists' reactions was important to the nature of the study as well. Since these individuals worked closely and/or on a daily basis with the UCP clients, it was necessary to evaluate their reactions regarding the disclosure booklet and its use.

However, the pilot study consisted of a small convenience sample with participants working in or receiving services solely from UCP in Bloomington, Illinois. The small-scale nature of the study impedes on the generalizability of using this particular disclosure method for individuals with ASD receiving supported employment services elsewhere. The ongoing study would need more participants across all respondent groups. The next logical step would be to

share booklets in the workplace in order to gather coworkers' responses and reactions to such disclosure.

Due to the non-experimental nature of the study, any changes in attitudes or working relationships as a result of reading the disclosure booklets were not able to be directly connected to their use. A continuation of this research is justified and would need to assess this type of disclosure in an experimental manner with ASD participants randomly assigned to booklet use conditions and no disclosure. An expansion of outcome measures is necessary to investigate the booklet's efficacy on employment success (i.e., length of employment, promotions, working relationships).

Further, the disclosure booklet needs to be investigated as a training tool for supported employment staff, so that they are able to adapt certain strategies of working with and properly assisting the supported employee. Considering the high drop-out rate and temporary nature of most job coach positions, adequate training specific to many different disabilities may be difficult to implement (Cramm, Tebra, & Finkenflugel, 2008). Thus, job coaches are ill-prepared to work closely with an individual who has ASD if they have not had prior experience or training.

Many individuals with disabilities are immediately stigmatized without a proper understanding of their behaviors or working abilities. Like any worker, individuals with ASD have a desire to work, perform well in their place of employment, and develop meaningful relationships. Yet, their condition is baffling to others, and many simply do not take the time to understand the individual's unique differences and qualities. Explanatory booklet disclosure may offer a way to help reduce the stigma and any misunderstandings associated with ASD. Although disclosure is a complex decision, it allows others the opportunity to learn more about ASD, and more importantly, the individual behind the ASD.

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Table 1

Participant Demographics

	<i>M</i>	<i>SD</i>
Age	25.17	4.62
	<i>N</i>	
Sex		
Female	2	
Male	4	
Disability		
Autism Spectrum Disorders	4	
Mild to Moderate Mental Imp.	2	
Employment Status		
Unemployed	1	
<12 Months	2	
>12 Months	3	
Receiving UCP Services		
<12 Months	2	
>12 Months	4	

Table 2

Data Completion

Client	Booklet	Phase I Client	Phase I Staff	Parent/Guardian	Phase II Job Coach
1	X	--	X	--	X
2	X	X	X	X	--
3	X	X	X	X	--
4	X	--	--	--	--
5	X	--	X	--	--
6	X	X	X	--	--

Note: "X" refers to missing data.

Table 3

Engagement in Process

Outcome Variables				
Ease of Development	Hard	Average	Easy	
Clients (3)	0	0	3	
Staff (5)	0	0	5	
Client Willingness to Share	I Don't Want To	I Don't Care	I Would Like To	I Would Love To
With Job Coach (3)	0	0	1	2
With Coworker (3)	0	0	2	1

Note: Numbers in parentheses represent total # of available responses.

Table 4

Cognitive Reactions

Outcome Variables			
	No	Neutral	Yes
Perceived Accuracy in Describing Client			
Clients (3)	0	0	3
Staff (5)	0	0	5
Parent (2)	0	0	2
Client's Understanding of Booklet Material	No	Neutral	Yes
Clients (3)	0	0	3
Staff (5)	0	0	5
Parent (2)	0	0	2

Note: Numbers in parentheses represent total # of available responses.

Table 5

Stakeholder Perceptions of Benefits of Sharing Booklet (Benefits Scale)

Respondents	Job Coach Version		Coworker Version	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Staff (5)	5.00	.00	4.95	.11
Parent (2)	4.63	.53	4.50	.35

Note: Benefits Scale scores ranged from 1-5 with “5” indicating respondents strongly agreed that sharing with a job coach or coworker was perceived as beneficial.

Table 6

Perceived Benefits and Risks

Benefits	
Client Responses	
2	Better understanding of why I am the way I am.
3	Because they will learn. The more people learn about me, it will help them too.
6	It will be able to explain something about me that's maybe hard for me to explain.
Parent Responses	
2	Coworkers would understand actions they would have wondered about otherwise. Others will realize that my son is quite open about how he is different and unique. Others will realize that he has a desire to do well and function at work.
3	Understanding her unique qualities. Understanding her social differences. Giving her visuals, checklists, and schedules that would help her to succeed.
Risks	
Client Responses	
2	There's a risk in dealing with bigots.
3	N/A
6	N/A
Parent Responses	
2	Would others read it? Others might be turned off and not try to accommodate his needs. He gets labeled as being different—opportunity for teasing by less mature people.
3	Misuse of information. Rationale for not hiring people with autism (too much work).

Note: All six clients not represented. Three of six completed questionnaire, and two had parents complete accompanying questionnaire. Client ID numbers provided to facilitate matching across responses.

Explanatory Disclosure Study Appendix

Informed Consent/Assent Forms

Informed Consent: Parent/Guardian Version

Informed Assent: UCP Client Version

Informed Consent: UCP Client Version

Informed Consent: UCP Staff Version

Informed Consent: Coworker Version

Phase I: Materials and forms related to booklet-making process

Explanatory Disclosure Booklet: Sample Text (ASD Version)

Explanatory Disclosure Booklet: Sample Text (Generic Version)

Phase I: Client Questionnaire

Phase I: Staff Questionnaire

Client Background Information Sheet

Phase II: Forms used after sharing booklet with job coach

Phase II: Job Coach Questionnaire

Parent/Guardian Response Form

Phase III: Forms used after sharing booklet with coworker

Phase III: Coworker/Supervisor Questionnaire

Phase III: Job Coach Questionnaire

Phase IV: Follow-up Forms

Phase IV: Client Follow-up Questionnaire

Phase IV: Job Coach Follow-up Questionnaire

Forms Related to Obtaining Informed Consent and Questionnaire Responses

UCP Staff Statement of Understanding & Agreement

Procedures for Obtaining Informed Consent from UCP Clients: Information for Case Managers

Procedures for Obtaining Informed Consent & Administering Questionnaires with Coworkers/Supervisors

CONSENT TO PARTICIPATE IN A RESEARCH STUDY (Parent/Guardian)

Title of Study: Explanatory Booklet Study
Principal Investigator: Linda Kunce, Ph.D., Department of Psychology
Phone Number: (309) 556-3663

Introduction: We invite your son/daughter with ASD, to participate in a research study. The study is under the direct supervision of Linda Kunce, PhD, with the assistance of Anna Genchanok, senior psychology student. We ask that you read this document and ask any questions you may have before agreeing to be in the study.

Background: We are inviting your son/daughter to participate in this research because they have been asked by UCP to make an explanatory booklet. The goal of the booklet is to help your son/daughter develop better working relationships by educating others regarding how their condition or disability influences their behavior at work.

The purpose of this *research study* is to learn how UCP clients, and their job coaches and coworkers, respond to the booklet.

Duration: During the study, we will ask your son/daughter to fill out two brief questionnaires (about 10 minutes each), one after they complete the booklet and one about 4-8 weeks later.

Procedures: Remember that your son/daughter will be developing their booklet with the help of UCP staff (not the research team). All decisions about booklet content and use will be made in line how you and your son/daughter typically make decisions with UCP staff.

Participation in the *research study* will involve:

1. Giving UCP permission to provide the researchers with your son/daughter's basic background information (gender, age, employment experiences, diagnoses).
2. After making the booklet, your son/daughter will be asked to complete a questionnaire about the booklet. We will also ask the UCP staff member who helped make the booklet with your son/daughter to complete a similar questionnaire.*
3. Deciding if your son/daughter wants to share the booklet with *you*, a *job coach* and/or a *coworker*. If they decide not to share, they will be done with the study. If they would like to share:
 - a. We will ask you to complete a questionnaire about the booklet.
 - b. We will ask their job coach to complete a questionnaire about the booklet.
 - c. We will ask their coworker to complete a questionnaire about the booklet.
 - d. We will also ask your son/daughter and their job coach to fill out a follow-up questionnaire about a month later.

*All questions we ask are focused on the booklet and its use (e.g., helpfulness, ease of understanding, possible benefits/risks).

Risks/Benefits: We do not expect participation in the study to create and additional risks or benefits beyond those involved in making and using the booklet. However, it is possible that completion of the brief questionnaires will have some unforeseen consequences. To minimize risk to your son/daughter, we have formatted the questionnaires so that the *booklet* and its use are being evaluated, rather than your son/daughter. You and your son/daughter are more than welcome to take a look at any of the questionnaires we plan to use.

We will thank your son/daughter by providing a \$5 gift card (e.g., Meijer, McDonalds).

Confidentiality: We will keep *all* participants’ answers confidential. First, we will not share your son/daughter’s specific responses with others in the study or vice versa (e.g., UCP client, UCP staff, coworker). Second, *your son/daughter’s name will never be attached to any questionnaire responses.* Your son/daughter will be assigned a unique identification code that will be written on all of their questionnaires. The identification list connecting names and identification codes will be maintained by a single UCP staff member. This person will not have access to the questionnaire responses and the researchers will not have access to the list. Therefore, nobody (not even the researchers) will be able to connect any responses with your son/daughter. Finally, although we plan to publicly describe the research for educational, research and/or local community purposes, it will be *impossible* for other people to identify your son/daughter or any other respondent in those presentations.

Voluntary Nature of the Study: *Participation in this study is completely voluntary.* Your son/daughter’s decision whether or not to participate will in no way jeopardize their relationship with UCP, the job site, or IWU. Further, if your son/daughter decides to participate in this study, they are free to withdraw from the study at any time.

Contacts & Questions: This study is under the direct supervision of Linda Kunce, PhD, with the assistance of Anna Genchanok. You may contact Dr. Kunce with any questions or concerns you may have about the study before giving your consent: (309) 556-3663 or lkunce@iwu.edu. If you have other questions or concerns regarding this study and would like to speak with someone other than the researchers, you may contact Dr. Jim Sikora, Institutional Review Board Chair, Illinois Wesleyan University, (309) 556-3163

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 STATEMENT OF CONSENT

I have read about procedures for this study, and my questions (if any) have been addressed. The information that is provided is confidential and will be used for research purposes only. I understand that my son/daughter’s participation is voluntary and that they may withdraw from the study at any time without penalty. If I or my son/daughter has any concerns about their experience in this study (e.g., unfair treatment), we may contact the Chair of the Institutional Review Board or the Chair of the sponsoring department of this research regarding these concerns.

You will be given a copy of this form to keep for your records.

I, _____ (print your first and last name), have read the information above. As a person 18 years or older and the parent/legal guardian of _____ (print son/daughter’s name) I voluntarily agree that my son/daughter participate in this research project.

 Your Signature

 Date

 Signature of Person Obtaining Consent

 Date

ASSENT TO PARTICIPATE IN A RESEARCH STUDY (UCP Client)

Title of Study: Explanatory Booklet Study
Principal Investigator: Linda Kunce, Ph.D., Department of Psychology
Phone Number: (309) 556-3663

Introduction: We invite you to participate in a research study. The study is under the supervision of Linda Kunce, PhD, with the assistance of Anna Genchanok, senior psychology student. We ask that you read this and ask any questions you may have before agreeing to be in the study.

Background: We are inviting you to participate in this research because you have been asked by UCP to make a booklet. The goal of the booklet is to help you develop better working relationships by educating others regarding how your condition or disability influences your behavior at work.

The purpose of this *research study* is to learn how you and your job coaches and coworkers respond to the booklet.

Duration: During the study, we will ask you to fill out two brief questionnaires (about 10 minutes each), one after you complete the booklet and one about 4-8 weeks later.

Procedures: After you have made your booklet, you will participate in the research study. This will involve:

1. Letting UCP staff give the researchers some of your basic information (age, job experiences).
2. Answering a few questions after you make your booklet, like what you enjoyed most about it.
3. Deciding if you want to share the booklet with your parent/guardian, a job coach and/or a coworker. If you decide not to share, you will be done with the study.
 - a. If you share the booklet with a parent or guardian, we will ask them some questions about the booklet.
 - b. If you share the booklet with a job coach, we will ask your job coach some questions about your booklet, like if they think it is useful.
 - c. If share the booklet with a coworker or supervisor, we will ask your coworker some questions about your booklet, like if they understood it.
 - d. About three weeks after you share your booklet with a coworker, you will be answer some questions asking if you enjoyed sharing your booklet with others.

You are welcome to take a look at the questions at the questions we plan to ask.

Risks/Benefits: We do not think that being in the study has any big risks for you, although it might be hard to answer some of the questions. You can skip any questions you do not want to answer. *We will give you a \$5 gift card to thank you for being in the study.*

Confidentiality: We will keep everyone's answers confidential. This means that we will not tell anyone your individual answers. In addition, we will record your answers using a special code number so that your name will not be on your forms. Although we plan to share the results of the study with other people, we will make sure that other people cannot tell what you, specifically, said.

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Voluntary Nature of the Study: Participation in this study is voluntary. This means that you are free to decide to be in the study or not. Whatever you decide is okay. Nothing bad will happen if you decide not to be in the study. Also, if you start in the study, you can still stop at any time without penalty. This will be okay, too

Contacts & Questions: Linda Kunce, PhD, and Anna Genchanok, are in charge of this study. You may ask any questions you have before signing this form. If you have questions later, you may contact Linda Kunce at (309) 556-3663 or lkunce@iwu.edu. If you have questions or concerns regarding this study and would like to speak with someone other than the researchers, you may contact Dr. Jim Sikora, Institutional Review Board Chair, Illinois Wesleyan University, (309) 556-3163

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STATEMENT OF ASSENT

You will be given a copy of this form to keep for your records.

The researchers have explained what will happen in the study. My questions have been answered. The answers I give will be kept private and used for research purposes. I understand that I am free to be in the study or not. It is also okay if I quit the study at any time. If I think that I was treated badly in this study, or have any other concerns about my experience, I may contact the Chair of the Institutional Review Board or the Chair of the sponsoring department of this research about my concerns.

I have read the information provided above. I, _____ (print your first and last name), voluntarily agree to participate in this research project.

Your Signature

Date

Signature of Person Obtaining Consent

Date

CONSENT TO PARTICIPATE IN A RESEARCH STUDY (UCP Client)

Title of Study: Explanatory Booklet Study
Principal Investigator: Linda Kunce, Ph.D., Department of Psychology
Phone Number: (309) 556-3663

Introduction: We invite you to participate in a research study. The study is under the supervision of Linda Kunce, PhD, with the assistance of Anna Genchanok, senior psychology student. We ask that you read this and ask any questions you may have before agreeing to be in the study.

Background: We are inviting you to participate in this research because you have been asked by UCP to make a booklet. The goal of the booklet is to help you develop better working relationships by educating others regarding how your condition or disability influences your behavior at work.

The purpose of this *research study* is to learn how you and your job coaches and coworkers respond to the booklet.

Duration: During the study, we will ask you to fill out two brief questionnaires (about 10 minutes each), one after you complete the booklet and one about 4-8 weeks later.

Procedures: Remember that you will develop and share your booklet with the help of UCP staff (not the research team). All decisions about what to include in the booklet and with whom you would like to share it will be made by you and UCP staff.

Participation in the *research study* will involve:

1. Giving UCP permission to provide the researchers with your basic background information (gender, age, employment experiences, diagnoses).
2. After making the booklet, you will be asked to complete a questionnaire about the booklet. We will also ask the UCP staff member who helped make the booklet to complete a similar questionnaire.*
3. Deciding if you want to share the booklet with your *parent/guardian*, a *job coach* and/or a *coworker*. If you decide not to share, you will be done with the study. If you would like to share:
 - a. We will ask your parent/guardian to complete a questionnaire about your booklet.
 - b. We will ask your job coach to complete a questionnaire about your booklet.
 - c. We will ask your coworker to complete a questionnaire about your booklet.
 - d. We will ask you and your job coach to fill out a follow-up questionnaire about a month later.

*The questions we ask are focused on the booklet and its use (e.g., helpfulness, ease of understanding, possible benefits/risks).

Risks/Benefits: We do not expect participation in the study to create any additional risks or benefits beyond those involved in making and using the booklet. However, it is possible that completion of the brief questionnaires will have some unforeseen consequences. To minimize risk to you, we have formatted the questionnaires so that the *booklet* and its use are being evaluated, rather than you. You are welcome to take a look at any of the questionnaires we plan to use.

We will thank you by providing a \$5 gift card (e.g., Meijer, McDonalds).

Confidentiality: We will keep *all* participants’ answers confidential. First, we will not share your specific responses with others in the study or vice versa (e.g., UCP client, UCP supervisor, UCP job coach, coworker). Second, *your name will never be attached to any questionnaire responses*. You will be assigned a unique identification code that will be written on all of your questionnaires. The identification list connecting your names and identification codes will be maintained by a single UCP staff member. This person will not have access to the questionnaire responses and the researchers will not have access to the list. Therefore, nobody (not even the researchers) will be able to connect your responses with your identity. Finally, although we plan to publicly describe the research for educational, research and/or local community purposes, it will be *impossible* for other people to identify you or any other respondent in those presentations.

Voluntary Nature of the Study: *Participation in this study is completely voluntary.* Your decision whether or not to participate will in no way jeopardize your relationship with UCP, your job site, or IWU. Further, if you decide to participate in this study, you are free to withdraw from the study at any time.

Contacts & Questions: This study is under the direct supervision of Linda Kunce, PhD, with the assistance of Anna Genchanok. You may contact Dr. Kunce with any questions or concerns you may have about the study before giving your consent: (309) 556-3663 or lkunce@iwu.edu. If you have other questions or concerns regarding this study and would like to speak with someone other than the researchers, you may contact Dr. Jim Sikora, Institutional Review Board Chair, Illinois Wesleyan University, (309) 556-3163

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STATEMENT OF CONSENT

I have read about procedures for this study, and my questions (if any) have been addressed. The information that I provide is confidential and will be used for research purposes only. I understand that my participation is voluntary and that I may withdraw at any time without penalty. If I have any concerns about my experience in this study (e.g., that I was treated unfairly or felt unnecessarily threatened), I may contact the Chair of the Institutional Review Board or the Chair of the sponsoring department of this research regarding my concerns.

You will be given a copy of this form to keep for your records.

I have read the information provided above. I, _____ (print your first and last name on the line), as a person 18 years or older, voluntarily agree to participate in this research project.

 Your Signature

 Date

 Signature of Person Obtaining Consent

 Date

CONSENT TO PARTICIPATE IN A RESEARCH STUDY (UCP Staff)

Title of Study: Explanatory Booklet Study
Principal Investigator: Linda Kunce, Ph.D., Department of Psychology
Phone Number: (309) 556-3663

Introduction: You are invited to participate in a research study. The study is under the direct supervision of Linda Kunce, Ph.D, with the assistance of Anna Genchanok, senior psychology student. We ask that you read this document and ask any questions you may have before agreeing to be in the study.

Background: We are inviting you to participate in this research because you have been asked by UCP to do one or more of the following: 1) help make a booklet, 2) read a booklet, and/or 3) help share a client's booklet with someone at their job site. The goal of the booklet is to help develop better working relationships by educating others regarding how your client's behavior at work is influenced by his or her condition (e.g., cognitive disability).

The purpose of this *research study* is to learn how UCP clients, their job coaches, and their coworkers/supervisors respond to the booklet.

Duration: This study will take place during a two to four month time period. As a research participant you will be asked to complete one or more questionnaires (5 – 10 minutes each).

Procedures: Depending on what you have been asked to do by UCP, your participation in the research study will involve one or more of the following:

- 1) *If you help a client develop a booklet:* You will be asked to complete a brief questionnaire evaluating the booklet (e.g., helpfulness, possible benefits/risks).
- 2) *If you are asked to read a client's booklet:* You will be asked to complete a similar questionnaire.
- 3) *If you help a client share his/her booklet in at the work site:* You will be asked to complete two questionnaires about the process of sharing the booklet, one right after you have shared it and the second three-four weeks later.

If you do any of these things more than once, we will ask you to complete a new questionnaire each time.

Risks/Benefits: If you decide to participate, we do not anticipate any major risks and/or discomforts for you; however, as with anything, some risks may be unforeseeable. For example, you may feel uncomfortable answering some questions regarding the booklet. Some benefits may include a better understanding of your client and strategies for working with him or her.

Each time you complete and submit a questionnaire we will offer you a snack as a small thank you for your time.

Confidentiality: We will keep *all* participants’ answers confidential. First, we will not share your specific responses with others in the study or vice versa (e.g., UCP clients, other UCP staff, coworkers/supervisors). Second, *your name will never be attached to your questionnaire responses.* You will be assigned a unique identification code that you will write on all of the questionnaires you complete. The identification list connecting names and identification codes will be maintained by a single UCP staff member. This person will not have access to questionnaire responses and the researchers will not have access to the list. Therefore, nobody will be able to connect your responses with your identity. Finally, although we plan to publicly describe the research for educational, research and/or local community purposes, it will be *impossible* for other people to identify you or any other respondent in those presentations.

Voluntary Nature of the Study: Participation in this study is completely voluntary. Your decision whether or not to participate in the research study will not affect your relations or responsibilities at work or with IWU. Further, if you decide to participate in this study, you are still free to withdraw from the study at any time without affecting those relationships.

Contacts & Questions: This study is under the direct supervision of Linda Kunce, PhD, with the assistance of Anna Genchanok. We encourage you to contact the investigators with any questions or concerns you may have about the study before giving your consent: Dr. Kunce can be reached at (309) 556-3663 or lkunce@iwu.edu. If you have other questions or concerns regarding this study and would like to speak with someone other than the researchers, you may contact Dr. Jim Sikora, Institutional Review Board Chair, Illinois Wesleyan University, (309) 556-3163

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 STATEMENT OF CONSENT

I have read about procedures for this study, and my questions (if any) have been addressed. The information that I provide is confidential and will be used for research purposes only. I understand that my participation is voluntary and that I may withdraw at any time without penalty. If I have any concerns about my experience in this study (e.g., that I was treated unfairly or felt unnecessarily threatened), I may contact the Chair of the Institutional Review Board or the Chair of the sponsoring department of this research regarding my concerns.

You will be given a copy of this form to keep for your records.

I have read the information provided above. I, _____ (print your first and last name), as a person 18 years or older, voluntarily agree to participate in this research project.

 Your Signature

 Date

 Signature of Person Obtaining Consent

 Date

CONSENT TO PARTICIPATE IN A RESEARCH STUDY (Coworker)**Title of Study:** Explanatory Booklet Study**Principal Investigator:** Linda Kunce, Ph.D., Department of Psychology, IWU **Phone:** (309) 556-3663

Introduction: You are invited to participate in a research study. The study is under the direct supervision of Linda Kunce, Ph.D. with the assistance of Anna Genchanok, senior psychology student. We ask that you read this consent form and ask any questions you may have before agreeing to be in the study.

Background: You are being invited to participate in this study as someone who works alongside a person who receives United Cerebral Palsy (UCP) supported employment services. You are also being invited because a UCP job coach has shared (or will share) a booklet with you. *The purpose of this research study is to learn how people respond to that booklet.*

Procedures: You will be asked to fill out a brief questionnaire (about 10 minutes). The questionnaire will ask you to share your reactions to the *booklet* you just read (e.g., ease of reading, helpfulness).

Risks/Benefits: If you decide to participate, we do not anticipate any major risks and/or discomforts for you; however, as with anything, some risks may be unforeseeable. For example, you may feel uncomfortable answering some questions about the booklet. *We will offer you a drink and snack to thank you for your time.*

Confidentiality: We will keep *all* participants' answers confidential. *Your name will never be attached to your questionnaire responses nor will your responses be shared with your coworker or the UCP job coach.* Your completed questionnaire will be sealed in an envelope and mailed directly to the IWU researchers. Although we plan to publicly describe the research for educational, research and/or local community purposes, it will be *impossible* for other people to identify you or any other respondent in those presentations.

Voluntary Nature of the Study: Participation in this study is completely voluntary. Your decision whether or not to participate will not affect your situation or responsibilities at work. Further, if you decide to participate in this study, you are still free to withdraw from the study at any time without affecting those relationships.

Contacts & Questions: This study is under the direct supervision of Linda Kunce, PhD, with the assistance of Anna Genchanok. You may contact Dr. Kunce with any questions or concerns you have about the study before giving your consent: (309) 556-3663 or lkunce@iwu.edu. If you have other concerns regarding this study and would like to speak with someone other than the researchers, you may contact Dr. Jim Sikora, Institutional Review Board Chair, Illinois Wesleyan University, (309) 556-3163

STATEMENT OF CONSENT

I have read about procedures for this study, and my questions have been addressed. The information that I provide is confidential and will be used for the research only. I understand that my participation is voluntary and that I may withdraw at any time without penalty. If I have any concerns about my experience in this study (e.g., that I was treated unfairly or felt unnecessarily threatened), I may contact the Chair of the Institutional Review Board or the Chair of the sponsoring department of this research regarding my concerns. I will be given a copy of this form to keep for my records.

I have read the information provided above. I, _____ (print your first and last name), as a person 18 years or older, voluntarily agree to participate in this research project.

Your Signature

Date

Signature of Person Obtaining Consent

Date

Date Form Last Revised: 11/21/10

Explanatory Disclosure Booklet: Sample Text (ASD Version)*

Introduction

Hi! I'm (your name). Like you, I have a family, I went to school, and I want to have a satisfying job. ... Continue by including 2 – 3 sentences that tell more about you: past employment experiences, special skills, hobbies or interests).

Something you may not know about me, is that I have autism (use the words you prefer: high functioning autism, Asperger syndrome, Aspie...).

Thank you for taking time to read this information. I hope you understand me so that we can work better together.

What *is* Autism? (Use preferred term)

Autism (or other preferred term) is a condition on the autism spectrum).

About 1 in 100 people have autism spectrum conditions.

The Autism Spectrum Disorders (ASD) are life-long, biologically-based conditions that affect how the brain works. People with ASD have social, communication, and behavioral differences that may be noticed or misunderstood by others.

To work effectively with someone on the spectrum, it helps to have: (1) a general understanding of ASD and (2) a unique understanding of the individual with whom you are working.

By reading this booklet, you will learn more about ASD as well as how it affects me.

Strengths as an Employee

Studies have shown that employees with ASD are rated highly by coworkers and employers on valuable characteristics such as reliability, honesty, attention to detail.

Here are some of my strengths as an employee: List some examples: Provided by ASD Individual and Case Manager

Some Differences You Might Notice

Communication

People with ASD and their coworkers may have difficulty communicating with each other. People with ASD may miss or misunderstand what other people say to them. Other people with ASD express themselves in atypical ways. Many people with ASD have difficulty reading and using nonverbal communication, such as tone of voice, facial expressions, or gestures.

What you might observe: Clients are prompted to provide examples of their own behaviors

What you might do: Clients are prompted to provide examples of what others can do to help improve their interactions

The following areas are similarly addressed:

Social Issues

Interests, Behaviors, & Sensory Issues

Thinking & Problem-Solving

The last pages of the booklet are devoted to space for individual additions, conclusion and helpful resources (books, organizations, contacts)

*A Sample booklet will be available upon request

Explanatory Disclosure Booklet: Sample Text (Generic Version)*

Introduction

Hi! I'm (your name). Like you, I have a family, I went to school, and I want to have a satisfying job. ... Continue by including 2 – 3 sentences that tell more about you: past employment experiences, special skills, hobbies or interests).

Something you may not know about me, is that I have (your disability)

Thank you for taking time to read this information. I hope you understand me so that we can work better together.

What *is* (Your condition)?

Write a brief (3-5 sentences) definition and description of your condition here.

To work effectively with someone with (your condition), it helps to have: (1) a general understanding of the condition and (2) a unique understanding of the individual with whom you are working.

By reading this booklet, you will learn more about my disability (or condition, disorder, or whichever word you prefer) as well as how it affects me.

Strengths as an Employee

Studies have shown that employees with disabilities are rated highly by coworkers and employers on valuable characteristics.

Here are some of my strengths as an employee: List examples: Provided by the client and Case Manager

Some Differences You Might Notice

Communication and Social Issues

Due to their differences, people with disabilities (or your condition) and their coworkers may have difficulty communicating and interacting with each other.

What you might observe: Clients are prompted to provide examples of their own behaviors

What you might do: Clients are prompted to provide examples of what others can do to help improve their interactions

The following areas are similarly addressed:

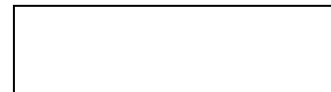
Social Issues

Interests, Behaviors, & Sensory Issues

Thinking & Problem-Solving

The last pages of the booklet are devoted to space for individual additions, conclusion and helpful resources (books, organizations, contacts)

*A Sample booklet will be available upon request



Phase I: Client

Directions: Please read and answer the following questions regarding the booklet-making process. Circle the best answer.

1. How easy was the booklet to complete for you?

3: *Easy *Average *Hard

4: *Yes *No
6: Do you think reading your booklet would be helpful for your job coach(es) with you at your job (e.g., coworkers, your supervisor)?

7. What do you like most about your booklet? *No *Sort of *Yes

Directions: These questions ask if you want to share your booklet with others.

1. How much do you want to share this booklet with one or more of your UCP job coaches?

*I don't want to *I don't really care *I would like to *I would love to
Optional: Please explain why.

2. How much do you want to share this booklet with someone that works closely with you at your job, such as a coworker or your supervisor?

*I don't want to *I don't really care *I would like to *I would love to
Optional: Please explain why.

Who else would you like to share this booklet with? Circle all of the people you would like to share it with.

*Nobody *Friend *Family Member *Customer at work *Teacher *Stranger
*Others (list) _____

Directions: These are the last questions we will ask about the booklet.

1. How do you think using this booklet will help you?

2. Do you think using this booklet will hurt you in any way? Please explain.

Directions: Please answer the following questions about you. Remember that all of your answers will be kept private.

1. I am : _____ Male _____ Female
2. Age (in years): _____
3. Are you currently working ? Check all that apply
 _____ Yes, Full time paid job _____ Yes, Part time paid job
 _____ Yes, Internship or Volunteer _____ No
4. If yes, about how many hours do you work each week (total) _____
5. Do you have a job for which you receive UCP services (such as job coach visits)?
 _____ No *If no, you are done with the questionnaire*
 _____ Yes

If yes, what is your job title? _____

If yes, about how long have you had this job? _____

If yes, about how many hours do you work each week? _____

If yes, please answer these last questions about your daily interaction with your coworkers at this job.

- | | | | |
|---|-----|---------|----|
| a) Do your coworkers treat you equally? | Yes | Sort of | No |
| b) Do coworkers exclude you or leave you out? | Yes | Sort of | No |
| c) Do coworkers make you feel welcome at work? | Yes | Sort of | No |
| d) Do coworkers make fun of you or mistreat you? | Yes | Sort of | No |
| e) Do coworkers act in a friendly way toward you? | Yes | Sort of | No |
| f) Do coworkers talk to you about things other than work? | Yes | Sort of | No |

Thank you! You are done. Please put your questionnaire in the sealed “Explanatory Booklet Study” box and pick up your \$5 gift card!



Phase I: Staff

Directions: Please read and answer the following questions regarding the booklet-making process for this client.

1. Descriptive information

- a. About how long did it take to make this client’s booklet?
Please estimate to the nearest half hour: _____
- b. To what degree did you use the provided template to guide the development of the book?(circle one): **Not at all** **A little**
 Moderately **A great deal**
- c. If you used the template, which did you use? ___ **ASD** ___ **Generic**

2. For these items, indicate how strongly you agree or disagree with each statement.

Strongly Agree	Strongly Disagree				
	Disagree			Neutral	
	1	2	3	4	5
a. From my perspective, it was easy to complete the booklet with this client.	1	2	3	4	5
b. I believe the booklet describes the client well.	1	2	3	4	5
c. I felt comfortable engaging the client in the booklet-making process.	1	2	3	4	5
d. I believe the client understands the information in the booklet.	1	2	3	4	5
e. I believe this client would benefit from sharing his/her booklet with the job coach .	1	2	3	4	5
f. I believe this client would benefit from sharing his/her booklet with a coworker .	1	2	3	4	5

3. Which of the following people do you feel would benefit from having the client share his/her booklet? (Circle all that apply.)

- *Friends *Family Members *Customers at work *Teachers
- *Coworkers *Job Coaches *Supervisors at work *Strangers
- * Others (list) _____

4. On the back of this form, please comment on anything noteworthy that occurred during the booklet-making process with this client. (e.g., difficulties, successes).

When you are finished, please place it in the sealed “Explanatory Disclosure Study” box and pick up your thank-you snack!



Client Background Information Form

Directions: (This form is to be completed by the supported employment staff.)
Please read and answer the following questions regarding your client.

1. Gender of client: ___Male ___Female
2. Age of client: _____
3. Disability or condition for which they receive supported employment services:

4. *Optional:* Additional diagnoses: _____
5. *Optional:* Intellectual Ability. If available, please provide the most recently available information regarding the client's cognitive functioning. If tests scores are available, include test name, date of assessment, and key scores (e.g., WAIS, 9/2007, Full Scale/Verbal/Performance IQ).

_____.

6. *Optional:* Current Level of Functioning. If available, please provide information regarding the client's current level of functioning, indicating assessment instrument and score (e.g., Global Assessment of Functioning Score)

_____.

7. How long has this client been receiving supported employment services from your agency?

8. If known, how long has this client been actively employed in the workforce (approximate number of years)? _____

9. Please describe the client's current job situation (include job titles, hours worked per week, and positions for which they are receiving supported employment services).

_____.

Parent/Guardian Response Form

Directions: Please read and answer the following questions about the booklet.

1. For these items, indicate how strongly you agree or disagree with each statement.

Strongly Agree	Strongly				
	Disagree			Neutral	
	1	2	3	4	5
a. This booklet was easy to read/understand.	1	2	3	4	5
b. This booklet describes my son/daughter very well.	1	2	3	4	5
c. I believe my son/daughter understands the information in the booklet.	1	2	3	4	5
d. Overall, I felt comfortable reading the information in the booklet.	1	2	3	4	5
e. I felt uncomfortable with the amount of personal information that was shared.					
f. Sharing this booklet with the person's <u>job coaches</u> would be...					
i. Beneficial	1	2	3	4	5
ii. Appropriate	1	2	3	4	5
iii. Risky	1	2	3	4	5
iv. Useful	1	2	3	4	5
g. Sharing this booklet with the person's immediate <u>coworkers</u> would be...					
i. Beneficial	1	2	3	4	5
ii. Appropriate	1	2	3	4	5
iii. Risky	1	2	3	4	5
iv. Useful	1	2	3	4	5

2. If your son/daughter shared this booklet in the workplace, what would the three main **benefits** be?

a) _____

b) _____

c) _____

3. If your son/daughter shared this booklet in the workplace, what would the three main **risks** be?

a) _____

b) _____

c) _____

4. Which of the following people do you feel would benefit from having your son/daughter share his/her booklet? (Circle all that apply.)

- *No One *Friends *Family Members *Customers at work
 *Teachers
 *Coworkers *Job Coaches *Supervisors at work *Strangers
 * Others (list) _____

5. If you are willing, please provide the following information so we can describe the respondents in this study.

a. I am : ___ Male ___ Female

b. I am: ___ Parent ___ Legal Guardian
 ___ Other (Please specify _____)

6. OPTIONAL: In the space below, please share *any* other responses you have to your son or daughter's booklet and its potential use.

Phase II: Job Coach

Directions: Please read and answer the following questions about the booklet.

1. Please write your unique ID number here: _____
2. For these items, indicate how strongly you agree or disagree with each statement.

Strongly Agree	Strongly Disagree				
	1	2	3	4	5
a. This booklet was easy to read/understand.	1	2	3	4	5
b. I learned a lot of new information about this client today.	1	2	3	4	5
c. This booklet describes the client very well.	1	2	3	4	5
d. Overall, I felt comfortable receiving the information in the booklet.	2	2	3	4	5
e. I felt uncomfortable with the amount of personal information that was shared.					
f. Sharing this booklet with other <i>job coaches</i> would be...					
v. Beneficial	1	2	3	4	5
vi. Appropriate	1	2	3	4	5
vii. Risky	1	2	3	4	5
viii. Useful	1	2	3	4	5
g. Sharing this booklet with the client's immediate <i>coworkers</i> would be...					
1 Beneficial	1	2	3	4	5
2 Appropriate	1	2	3	4	5
3 Risky	1	2	3	4	5
4 Useful	1	2	3	4	5

- 3 What did you like best about the client's booklet?

- 4 What did you like least or find problematic about the client's booklet?

5 How did the booklet influence *your* interest and willingness to do the following:

	Strongly Decreased	2	No Influence	3	4	Strongly Increased
a. Work with the client	1	2	3	4	5	5
b. Have the client assigned to you	1	2	3	4	5	5
c. Be a mentor or "go to" person for this client	1	2	3	4	5	5
d. See the client as an equal	1	2	3	4	5	5
e. Collaborate with the client on work tasks	1	2	3	4	5	5

6 If you were to take an active role in sharing this booklet with the client's immediate coworkers, to what degree do you think coworkers would view you as:

	Less than Usual	2	3	4	5
a. Competent	1	2	3	4	5
b. Capable	1	2	3	4	5
c. Friendly	1	2	3	4	5
d. Warm	1	2	3	4	5
e. Skilled at tasks	1	2	3	4	5
f. Able to work well with others	1	2	3	4	5

7 If you, as a job coach, were going to help this client share the booklet in the workplace, what would the three main **benefits** be?

- a) _____

- b) _____

- c) _____

- _____

8. If you, as a job coach, were going to help this client share the booklet in the workplace, what would the three main **risks** be?

- a) _____

- b) _____

c)

9. Confidence Scale. How did the booklet influence your *confidence* that you could effectively do the following things with your client?

	Strongly Decreased 1	Somewhat Decreased 2	No Influence 3	Somewhat Increased 4	Strongly Increased 5
1. Interact with the client	1	2	3	4	5
2. Make changes in my own job coaching behaviors to adjust to client's possible differences.	1	2	3	4	5
3. Be an effective job coach to this person.	1	2	3	4	5
4. Put time and effort into understanding the needs and preferences of this client.	1	2	3	4	5
5. Accept this client even if he/she does unusual things (e.g., unexplained agitation).	1	2	3	4	5
6. Be a vocal advocate for this client in the workplace.	1	2	3	4	5
7. Be an effective mentor or "go to" person for this client.	1	2	3	4	5
8. Help this client become fully integrated into the social life of the workplace.	1	2	3	4	5

Demographic Information: Please provide the following information so we can describe our sample of respondents. *This information will not be connected to your other responses in any report of research results. You may skip any questions you prefer not to answer.*

1. Basic Information: *If you completed one of these questionnaires before and wrote your unique ID # on page one, you can skip this first set of items. If not, please answer.*
 - a. I am : Male Female
 - b. Age (in years): _____
 - c. How long have you been working as a job coach or in a similar position?

 - d. Have you been/are you a job coach for this person? Yes No

2. Please answer the following the questions using the provided scale:

	Moderately 1	Very much 2	Not at all 3	4	5
a. How well do you know this client?	1	2	3	4	5
a. Have you had any formal on-the-job training regarding disabilities (here or in a prior position)?	1	2	3	4	5
b. Overall, to what degree have you been exposed to people with disabilities?	1	2	3	4	5
c. Have you had any formal on-the-job training regarding autism here or in a prior position?	1	2	3	4	5
d. Overall, to what degree have you been exposed to people on the autism spectrum ?	1	2	3	4	5

Thank you for taking time to complete this questionnaire! Please submit it in the “Explanatory Disclosure Study” box and select a thank-you snack!

Phase III: Coworker/Supervisor

Directions: Please read and answer the following questions regarding the booklet provided to you today by the UCP job coach. When the items refer to your coworker, please think about the person supported by the UCP job coach.

1. What is *your* relationship to this coworker?

*Supervisor *Coworker *Other _____

2. For these items, indicate how strongly you agree or disagree with each statement.

	Strongly				
	Strongly	Disagree			Neutral
Agree					
a. The booklet was easy to read/understand.	1	2	3	4	5
b. I learned a lot of new information about my coworker today.	1	2	3	4	5
c. The booklet describes my coworker well.	1	2	3	4	5
d. I felt uncomfortable with the amount of personal information that was shared.	1	2	3	4	5
e. Overall, I felt comfortable receiving the information in the booklet.					
f. Sharing this booklet with other immediate <u>coworkers</u> would be...					
i. Beneficial	1	2	3	4	5
ii. Appropriate	1	2	3	4	5
iii. Risky	1	2	3	4	5
iv. Useful	1	2	3	4	5

3. What did you like best about the booklet?

4. What did you like least or find problematic about the booklet?

5. How did the booklet influence *your* interest and willingness to do the following:

	Strongly Decreased		No Influence		Strongly Increased
Work with the coworker	1	2	3	4	5
Have the coworker assigned to you	1	2	3	4	5
Be a mentor or “go to” person for this coworker	1	2	3	4	5
See the coworker as an equal	1	2	3	4	
Collaborate with the coworker on work tasks		5			
	1	2	3	4	5

6. Based on the your interaction with the job coach as the booklet was shared, to what degree did the *job coach* seem:

	Not at All Much		Neutral		Very
a. Competent	1	2	3	4	5
b. Capable	1	2	3	4	5
c. Friendly	1	2	3	4	5
d. Warm	1	2	3	4	5
e. Skilled at tasks	1	2	3	4	5
f. Able to work well with others	1	2	3	4	5

7. If the booklet provided to you today was shared with others in the workplace, what would the three main **benefits** be?

a) _____

b) _____

c) _____

—

8. If the booklet provided to you today was shared with others in the workplace, what would the three main **risks** be?

- a) _____

 b) _____

 c) _____

9. **Confidence Scale.** How did the booklet influence your *confidence* that you could effectively do the following things with your coworker?

	Strongly Decreased	Somewhat Decreased	No Influence	Somewhat Increased	Strongly Increased
a. Interact with the coworker	1	2	3	4	5
b. Make changes in my own behaviors to adjust to coworker's possible differences.	1	2	3	4	5
c. Be an effective coworker to this person.	1	2	3	4	5
d. Put time and effort into understanding the needs and preferences of this coworker.	1	2	3	4	5
e. Accept this coworker even if he/she does unusual things (e.g., flap hands, stand too close, verbal outbursts, unexplained agitation).	1	2	3	4	5
f. Be a vocal advocate for this coworker in the workplace.	1	2	3	4	5
g. Be an effective mentor or "go to" person for this coworker.	1	2	3	4	5
h. Help this coworker become fully integrated into the social life of the workplace.	1	2	3	4	5

Demographic Information

Please provide the following information so we can better describe our sample. *Remember that your name will never be connected with your responses. You may skip any questions you prefer not to answer.*

Directions: Please read and answer the following questions.

1. I am: ___ Male ___ Female

2. Age (in years): _____

3. Please answer the following the questions using the provided scale:

Moderately

Very much

Not at all

- | | | | | | |
|---|----------|----------|----------|----------|----------|
| a. How well do you know this coworker? | 1 | 2 | 3 | 4 | 5 |
| b. Overall, how welcoming do you think your place of business is for employees with disabilities? | 1 | 2 | 3 | 4 | 5 |
| c. Have you had any formal job training regarding disabilities (here or in a prior position)? | 1 | 2 | 3 | 4 | 5 |
| d. Overall, to what degree have you been exposed to people with disabilities in general? | | | | | |

Thank you for taking time to answer this questionnaire. Please put it into the provided envelope, seal it, and have it put in the mailbox you enjoyed your snack!

Phase III: Job Coach

Directions: Please read and answer the following questions regarding your experience sharing the client's booklet with the coworker.

- Write your unique ID number here: _____
- How long did it take to share the booklet with the coworker?

- Overall, the experience of sharing the booklet was:

*Extremely negative		*Neutral		*Extremely Positive
1	2	3	4	5
6				7

- Please answer the following questions.

	Not at All	Neutral	Very Much
a. Did sharing the booklet seem useful?	1	2 3	4 5
b. How comfortable did you feel?	1	2 3	4
c. How comfortable did the coworker seem?	5		
d. Did the process generate discussion?	1	2 3	4
e. Did the coworker seem engaged in the interaction?	5		
	1	2 3	4
	5		
	1	2 3	4
	5		

5. Optional comments regarding the above questions:

6. Please include any noteworthy reactions or questions from the coworker (continue on back as needed):

Phase IV: Client Follow-Up

Directions: Please read and answer the following questions regarding your disclosure booklet.

1 How much did you like making and using the booklet?

*I didn't like it *No preference *I liked it a lot

2 Who have you shared your booklet with? Circle all of the answers that apply.

*Friend *Coworker *Family Member *Customer at work
 *Teacher *Job Coach *Supervisor at work *Stranger
 * No one *Other

3 If you shared your booklet with a job coach, was it a good experience?

*Yes *Sort of *No

4 If you shared your booklet with a coworker, was it a good experience?

*Yes *Sort of *No

5 Did using the booklet help you in any way? *Yes *No
If yes, how did using the booklet help you?

- 6 Did using the booklet cause problems in any way? *Yes *No**
If yes, how did using the booklet cause problems?

- 7. Directions:** Please read and answer the following questions regarding your daily interactions with your coworkers since sharing the booklet. Circle the best answer.

- | | | | |
|---|-----|---------|----|
| 1. Do your coworkers treat you equally? | Yes | Sort of | No |
| 2. Do coworkers exclude you or leave you out? | Yes | Sort of | No |
| 3. Do coworkers make you feel welcome at work? | Yes | Sort of | No |
| 4. Do coworkers make fun of you or mistreat you? | Yes | Sort of | No |
| 5. Do coworkers act in a friendly way toward you? | Yes | Sort of | No |
| 6. Do coworkers talk to you about things other than work? | Yes | Sort of | No |

Optional: In the space below, write any comments you would like about making or using the booklet.

Thank you for taking time to complete this questionnaire! Please submit it in the “Explanatory Disclosure Study” box and select a thank-you message!

Phase IV: Job Coach Follow-Up

Directions: Please read and answer the following questions regarding the booklet-reading process for this client.

1. Unique ID # _____
2. For these items, indicate how strongly you agree or disagree with each statement.

Strongly Agree		Strongly Disagree		Neutral	
a. Sharing this booklet with me, as a <i>job coach</i> , was ...					
i. Beneficial	1	2	3	4	5
ii. Appropriate	1	2	3	4	5
iii. Risky	1	2	3	4	5
iv. Useful	1	2	3	4	5
b. Sharing this booklet with the <i>coworker</i> at the job site seemed to be...					

v. Beneficial	1	2	3	4	5
vi. Appropriate	1	2	3	4	5
vii. Risky	1	2	3	4	5
viii. Useful	1	2	3	4	5

3. Overall, were there any benefits or positive outcomes of using the booklet (for the client, you, or coworkers/job site)? If yes, what?

4. Overall, were there any negative or problematic outcomes of using the booklet (for the client, you, or coworkers/job site)? If yes, what?

5. **Optional:** On the back, write any other comments or suggestions you would like about the booklets or this study.

Submit your form in the “Explanatory Disclosure Study” box and select a thank-you snack!

Procedures for Obtaining Informed Consent & Questionnaire Responses
UCP Staff Statement of Understanding & Agreement (Form 1 of 3)

Dear UCP Staff,

Thank you for agreeing to describe the Explanatory Booklet Study to your clients and their coworkers. In this role, you may end up doing on of the following things:

- (1) Getting informed consent from a UCP client,*
- (2) Getting informed consent from a coworker/supervisor at the client’s job site and administering a questionnaire to that person.*

According to ethical guidelines for research, informed consent and data collection must be done according to the procedures described in the proposal reviewed by the appropriate ethics board (in this case, the IWU Institutional Review Board). Therefore, please read and sign this form to indicate that you: were given the appropriate procedure sheet, understand the procedures, and agree to follow those procedures.

Sincerely, Linda Kunce & Anna Genchanok, IWU

I was provided with the procedures sheet for “Procedures for Obtaining Informed Consent from a UCP Client.” I have read and understand the procedures and agree to follow them.

Printed Name & UCP Job Title: _____
Signature _____ Date _____
Witness _____

I was provided with the procedures sheet for “Procedures for Obtaining Informed Consent & Administering Questionnaire with Coworkers/Supervisors.” I have read and understand the procedures and agree to follow them.

Printed Name & UCP Job Title: _____
Signature _____ Date _____
Witness _____

Procedures for Obtaining Informed Consent from UCP Clients: Information for Case Managers (Form 2 of 3)

1. If a client has decided to make an explanatory disclosure booklet as part of their supported employment services, please invite the client to participate in the related research study if they
 - a. are age 18 or older
 - b. have an autism spectrum condition or another cognitive, social or intellectual disability
 - c. have sufficient verbal and intellectual ability to engage in the booklet making process and respond to the questionnaires (either independently or with UCP staff assistance)

2. At some point in the process of describing the study, have the client/guardian read the appropriate informed consent form (or read it to them). Use the correct form as follows:
 - a. **Informed Consent (UCP Client):** Use if client is an independent adult (i.e., no legal guardian).
 - b. **Informed Consent (Parent/Guardian):** If the client *has* a legal guardian, the *guardian* must read/sign this form
 - c. **Informed Assent (UCP Client with Guardian):** If the client *has* a legal guardian, UCP *client* reads/signs this form.

3. Help the client understand what they are being asked to do:
 - a. Give UCP staff permission to provide the researchers with basic background information
 - b. Fill out a questionnaire about their booklet after they have made it.
(Clients that decide not to share their booklet are done with the research study at this point).
 - c. If they share their booklet with a job coach and/or someone at their work site as part of their supported employment services), they are also being asked to
 - i. Give permission for the job coach and coworker/supervisor(s) to fill out questionnaires.
 - ii. Fill out a follow-up questionnaire 3 – 4 weeks later

4. Information to emphasize when describing the study and reviewing the informed consent.
 - a. Participation in the research study is completely voluntary. They are free to decline participation or withdraw at any time without penalty.
 - b. Participation in the research study (yes or no) will not influence their relationship with UCP, the worksite, or IWU (e.g., if they have decided with UCP staff that they want to develop a booklet but do *not* agree to be in the study, they can still develop the booklet.)
 - c. All information will be kept confidential. The use of code numbers means that the researchers will never be able to link their responses with their names. In addition, UCP staff and coworkers will never see their responses (or vice versa).
 - d. Clients that are concerned about being judged by others will also want to know that all questionnaires ask about the booklet and its use. They are welcome to look over the questions that will be asked if they want.

- e. The client will be thanked for his/her participation with a \$5 gift card.
5. Ask for and answer the client's questions. If you cannot answer a question, please contact or help the client/guardian contact the researchers (contact information is on the informed consent form).
6. **Have the client and guardian (when appropriate) sign and date their informed consent/assent form. You should sign as the person obtaining consent.**
7. Provide the client/guardian with an unsigned copy of the consent/assent for their own records and put the signed informed consent in the sealed research form box at UCP.
8. Request that the UCP staff member in charge of maintaining the ID list assign a code number to the client. (This number should *not* be put on the informed consent form although it will be on all subsequent forms.)

**Procedures for Obtaining Informed Consent & Administering Questionnaires with
Coworkers/Supervisors (Form 3 of 3)**

1. You will invite coworker/supervisors of UCP clients to participate in the research study IF and ONLY IF
 - a. You have been assigned in your role as a UCP staff member to help the client share his or her booklet in the workplace. (Note: decisions about how, when, and with whom to share the booklet are the responsibility of the UCP client and UCP staff—not the researchers.)
 - b. The UCP client is participating in the research study (i.e., they have signed the informed consent form).
 - c. The coworker/supervisor is 18 years or older

2. At the time you meet with the coworker/supervisor to share and discuss the booklet, you will invite the person to participate in the research study, explaining that he/she will be asked to
 - a. Read and sign an informed consent form
 - b. Fill out a brief questionnaire about the client's booklet (5 – 10 minutes)

3. Give the person **Informed Consent form** to read. After they have read the form, please mention the following points:
 - a. Participation is fully voluntary. They are free to decline participation or withdraw at any time without penalty.
 - b. Participation in the research study (yes or no) will not influence their relationship with UCP, the worksite, or IWU.
 - c. All information will be kept confidential. Their name will never be attached to their answers. Their completed forms will be mailed directly to the researchers (in the provided envelopes), so neither you nor the client (or anyone else associated with UCP) will know how they respond.
 - d. They will be thanked by the researchers with a free snack and drink.

4. Ask for and answer the person's questions. If you cannot answer a question, please contact or help the client/guardian contact the researchers (contact information is on the informed consent form).

5. **Have the coworker/supervisor sign and date their informed consent/assent form. YOU should sign the form as the person obtaining consent.**

6. Put the signed informed consent in one of the provided envelopes and seal it. Give the coworker/supervisor an unsigned copy of the consent form to keep.

7. After the coworker/supervisor has read the booklet and discussed content with you, give him/her the **Phase III: Coworker/Supervisor Questionnaire** to complete.
 - a. Please give the person privacy as they complete the form (e.g., if you have been sharing a table, move to another location).
 - b. The coworker/supervisor should put their completed questionnaire into the second provided envelope and seal it.

8. Drop both envelopes immediately into the mail at the workplace so that they are sent directly back to the IWU researchers.

Thank You!